FOLLOW-THROUGH OF PALLIATIVE CARE

AFTER NURSING HOME ADMISSION

by

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ABSTRACT

Clinical practice guidelines and accrediting agencies emphasize the need for palliative care in nursing homes and care coordination between the hospital and nursing home. However, it is unclear how care is managed for patients discharged to nursing homes after a hospital-based palliative care consult. The purpose of this study was to describe the continuity of care, experiences, and outcomes of residents in a nursing home after palliative care consult during hospitalization. A qualitative descriptive approach was used to enroll a sample of 12 adults, 60 years or older, with a life expectancy of at least 7 days, who received a palliative care consult during hospitalization, and who were discharged to a nursing home without hospice support. Participants' charts were reviewed for clinical information at five time points from hospital discharge to 100 days after nursing home admission. Face-to-face semistructured interviews were conducted, individual chart data were extracted, and care trajectories were mapped. Audio recordings of the interviews were transcribed, and transcripts were imported into a qualitative data analysis software program that was used to organize and manage all data. Content analysis was employed to identify codes, categories, and themes. The mean age of this sample was 80 years (range 62–95). All participants were seriously ill and received goals-of-care conversations facilitated by a palliative care team in the hospital; care preferences ranged from comfort care only to aggressive life-prolonging treatments. However, all participants accessed the Medicare skilled nursing facility benefit upon nursing home

admission, which indicated a need for rehabilitative or restorative care. None of the participants accessed hospice services in the nursing home. Study findings indicate that despite receiving a palliative care consultation, continuity in care was largely insufficient, and palliative care follow-up was episodic. Three influences on care discontinuity for this complex group of patients are care-setting transitions, individual patient- and family-level factors, and system-level interference. To improve palliative care throughout illness trajectory, older adults need better access to ongoing community and primary palliative care.

This dissertation is dedicated to all who face serious illness.

May this work advance access and delivery of palliative care.

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CHAPTER 1

INTRODUCTION

Clinical practice guidelines and accrediting agencies emphasize the need not only for palliative care in nursing homes but also for care coordination between the hospital and the nursing home. However, it is unclear how care should be managed for patients who are discharged to nursing homes after a hospital-based palliative care consult. This study sought to provide an in-depth description of posthospital nursing home care for residents with life-limiting serious illness who received a palliative care consult during hospitalization.

The purpose of this qualitative descriptive study was to describe palliative care follow-through, resident outcomes, and resident perceptions of care after being admitted to a nursing home. The investigator approached 37 potential participants for the study after they had received a palliative care consult while hospitalized and were given a posthospital discharge plan to a nursing home without hospice. Of the potential participants, 12 enrolled in the study. Semistructured interviews and chart reviews provided the data for analysis. The perspectives of residents and/or family members were used to illustrate perceptions of care delivery.

This chapter begins with a review of the study's context. Following the context and background section are the problem statement, the study purpose, and research

questions that explicate the study aims. Next, the study's significance is outlined with potential implications. The definitions of terms explain how the terms are used in this study. The chapter concludes with a summary of the dissertation's organization.

Background

Palliative care is an important interdisciplinary approach to health care for older adults living with advanced or serious life-limiting illness and complex care needs (National Consensus Project for Quality Palliative Care, 2013; World Health Organization, 2015). The primary components of palliative care practice include symptom management, psychosocial and spiritual support for the patient and family, and goals-of-care discussions focused on informed decision making and coordination of care.

Despite being promoted as an effective method for delivering high-quality care to nursing home residents with life-limiting illness (Meier, Lim, & Carlson, 2010), palliative care is not widely available in the nursing home setting (Meier & Beresford, 2010; Miller & Han, 2008). However, two thirds of U.S. hospitals with more than 50 beds report the presence of a palliative care team (Center to Advance Palliative Care, 2015), which means that hospitalized patients discharged to a nursing home may only have contact with hospital-based palliative care teams. The potential disruption in palliative care service upon hospital discharge and nursing home admission may lead to inadequate coordination of symptom management and lack of communication about goals, values, and preferences for care.

The literature does not describe integration and follow-through of palliative care after hospitalization, including whether recommendations are followed and implemented

in the nursing home. Only one research team studied the patient and family experience of discharge planning after palliative care consult, but their work did not focus exclusively on nursing home care (Benzar, Hansen, Kneitel, & Fromme, 2011). The researchers who conducted this qualitative study determined that discussions about prognosis, symptom management, and patient and caregiver questions were the three major areas of concern after discharge, even for those who went to a nursing home. These findings demonstrate clear gaps in our understanding of the posthospital experience and follow-through with formal care support in a nursing home after a hospital-based palliative care consult. Two implications of the Benzar et al. (2011) study are a need for studying (a) how well pain and symptoms are being managed and (b) how promptly prognoses and goals of care are being readdressed after hospital discharge.

Challenges to delivering palliative care in U.S. nursing homes include frequent and burdensome care-setting transitions; inadequate staff training, accompanied by high turnover; poor communication among clinicians; a facility's lack of acceptance of palliative care; and a work environment that focuses on task completion rather than individualized, resident-centered care (Center to Advance Palliative Care, 2008; Ersek & Wilson, 2003; Furman, Pirkle, O'Brien, & Miles, 2006; Hodgson & Lehning, 2008; Liao & Ackermann, 2008). Consequences of these barriers include unintended emphasis on aggressive rehabilitation over palliative goal-oriented care (Travis et al., 2002); diminished focus on person-centered care that values individual, identity-enhancing care for residents at the end of life (Trotta, 2007); and missed opportunities for symptom management, including psychosocial and spiritual support (Thompson & Oliver, 2008).

Several national organizations have advocated for the delivery of palliative care

throughout patient care transitions. The Agency for Healthcare Research and Quality (Lorenz et al., 2004) recommends increased research about palliative care across multiple settings, including continuity of palliative care between the hospital and nursing home. Effective care transitions are seen as an important way to reduce preventable hospital readmissions, which cost Medicare approximately $26 billion each year (U.S. Department of Health and Human Services, 2011). The National Consensus Project's *Clinical Practice Guidelines for Quality Palliative Care* (2013) delineates that the most effective method for maintaining continuity in palliative care delivery is through coordination of care across health care and community settings.

Researchers and clinicians report that care transitions are especially important for those patients not discharged to hospice care (Meier & Beresford, 2008). This is especially problematic for those patients with complex care needs and serious or terminal illness who use the posthospital Medicare skilled nursing facility (SNF) benefit in nursing homes (Aragon et al., 2012; Boling, 2012; Miller, Lima, & Mitchell, 2012). The SNF benefit can be used up to 100 days after a hospital stay for skilled nursing care and rehabilitation (U.S. Department of Health and Human Services, 2007). After this benefit period, residents who need additional nursing home care continue to receive custodial care at the nursing facility. Those who have regained their functional status by meeting rehabilitation goals no longer need skilled nursing care and, if well enough, are discharged home or to another setting. At 7 and 21 days following admission, a care plan is developed or revised in order for each resident to continue receiving the SNF benefit, anticipate transition to another level of care (e.g., custodial care or hospice care), or go to a community home. There has, however, been increased interest and concern about use of

the SNF benefit during the last few months of life due to its focus on life-prolonging care and rehabilitation. In addition, researchers report that older adults with advanced dementia who use the SNF benefit without Medicare hospice may have unmet care needs compared to those using hospice in the last few months of life (Miller et al., 2012). Those with dementia—a serious and potentially life-limiting illness—have impaired capacity to acquire new and different skills, which is the focus of rehabilitative care.

Aragon at al. (2012) found that one third of older adults who receive care under the SNF benefit die within six months of death. Although these findings indicate SNF benefit use by residents approaching death, the researchers of this retrospective study of survey data were unable to capture the quality of care outcomes, such as the presence and management of pain and other symptoms, and the ways in which goals of care were addressed for decedents during the SNF benefit period. In a separate retrospective cross-sectional study, Miller at al. (2012) used Minimum Data Set assessments to evaluate the pain, dyspnea, and health care use experienced by nursing home residents with advanced dementia. Findings indicate a lower likelihood of symptom burden for decedents with Medicare hospice enrollment after SNF benefit versus use of only the SNF benefit.

Together, these studies offer a global examination of the nursing home system but do not describe day-to-day care, resident experiences, or perceptions of care. Prospective study and data collection from the resident viewpoint, together with a description of care outcomes, will enhance existing research. A critical implication of these studies is the growing need for an in-depth description of posthospital nursing home care with and without hospice and the SNF benefit for nursing home residents who have life-limiting serious illness.

Public opinion research reveals that 62% of U.S. health care consumers over 65 years of age want access to palliative care if they have a serious illness (Center to Advance Palliative Care, 2011). In the survey, palliative care was defined as an extra layer of medical care for those with serious illness to provide relief of symptoms and improve quality of life. In an attempt to improve access to palliative care, several states have introduced legislation to blend palliative care into usual medical care (Gever, 2008). Other states require health professionals to complete continuing education in end-of-life care and pain and symptom management (Maryland Attorney General, n.d.).

Problem Statement

Despite clear evidence that older adults in the United States want access to palliative care and that palliative care is an acceptable and important treatment option for people with serious illness, many barriers impede successful implementation. Hospital-based palliative care teams are seeing an increase in the use of nursing homes as a site of posthospital care after palliative care consultation (E. K. Fromme, personal communication, December 6, 2012). Hospice is often underused on initial nursing home admission to take advantage of the SNF benefit (Miller et al., 2012). For these patients, it is unclear whether hospital-initiated palliative care recommendations are implemented in the nursing home, as recommendations may not align with SNF benefits and services.

Study Purpose and Research Questions

There is limited research on older patients who receive inpatient palliative care consultation that includes postdischarge outcomes (Benzar et al., 2011). The purpose of

this qualitative descriptive study, therefore, was to describe continuity of palliative care, experiences, perceptions, and outcomes in the nursing home for residents after they receive a palliative care consult during hospitalization. Semistructured interviews and chart reviews were conducted to describe and improve understanding of palliative care delivery.

The following aims and research questions (RQs) were addressed:

Aim 1) Describe the continuity of a patient's palliative care plan from the hospital to the nursing home.

RQ 1: What palliative care recommendations made during hospital palliative care consult are followed through and received by residents in the nursing home?

Aim 2) Describe the experience of patients admitted to the nursing home following discharge from a hospital with a palliative care consult.

RQ2: What are the immediate and long-term outcomes (e.g., goals of care, advance-care planning, symptom management, psychosocial support, spiritual care, nursing, rehabilitation, medical care) for residents in the nursing home after a palliative care consult during hospitalization?

RQ3: How do patients and/or families perceive pain and symptom management, adherence to goals of care, and psychosocial support in nursing homes after hospital discharge with a palliative care consult?

Research Approach

The investigator used a qualitative descriptive approach with semistructured interviews and chart reviews. After approvals from the University of Utah Institutional

Review Board and from the required hospital and nursing home, the investigator followed 12 patients who had been seen by a hospital-based palliative care team and who were then provided with a discharge plan to a nursing home. For those care recipients who could not participate in a conversation (semistructured interview), a family member was invited to provide the care recipient's (also referred to as patient or resident) perspective in the interviews. De-identified chart review data and transcribed interviews were organized in NVivo v9 according to participant number. Analysis began in systematic steps with First and Second Cycle coding methods (Saldana, 2009). An iterative process was used throughout data analysis to identify categories and themes, which provided a framework for reporting study results. Attention to trustworthiness was achieved through use of methodological triangulation, prolonged involvement in data collection, field notes, memos reflecting decisions during data analysis, and acknowledgment of assumptions through journaling and debriefing with the dissertation chair (Bloomberg & Volpe, 2008; Farmer, Robinson, Elliott, & Eyles, 2006).

Significance

Despite the benefits, palliative care has not been widely implemented in U.S. nursing homes. It is unclear how nursing homes are managing follow-through after care-setting transition for residents who have had a hospital-based palliative care consult. The results of this study's person-centered perspective describe perceptions of physical and psychosocial care that may affect quality of life and improve understanding of outcomes for individuals with serious life-limiting illness in nursing homes. Three areas of significance for this study have the potential for informing future research, practice, and

policy.

First, as detailed above, resident and family descriptions of nursing home care and posthospital palliative care experiences can increase the understanding about the barriers to and facilitators of palliative care in nursing homes. Eliciting participant values regarding their care preferences and goals of care while they are experiencing life-limiting illness helps determine the best next steps for additional study to meet the needs of residents and family members.

Second, nursing homes are a common setting for postacute care. In-depth examination of nursing home care after hospital palliative care consult (e.g., follow-through) is necessary to inform clinical practice and to guide initiatives that promote palliative care in nursing homes. Researchers cannot meaningfully inform future clinical practice guidelines without high-quality descriptions of current care processes.

Third, researchers report an increasing trend in adults over 65 years of age dying in U.S. nursing homes, with growth in decedents from 21% in 1989 to 28% in 2007 (National Center for Health Statistics, 2011). Nursing homes are a discharge destination for up to one third of patients who receive palliative care during hospitalization (Cowan, 2004; Holloway et al., 2010; Morrison et al., 2008). Without palliative care in nursing homes, the population of older adults in nursing homes living with and dying from serious life-limiting illness is at risk for unrecognized and/or undertreated pain and symptoms, poor communication about the disease process, and lack of psychosocial support and individual care based on goals of treatment (Meier & Sieger, 2007). Findings of this study will inform future research priorities about palliative care in nursing homes, with the potential of impacting policies regarding end-of-life care.

Definition of Terms

Advance-care planning: Care that is planned and decided upon by eliciting a patient's or resident's values and preferences for future treatments, primarily through a series of meetings with the patient or resident, family members, or legally authorized representatives (LARs). Such meetings are also called goals-of-care discussions, care-planning meetings, and family meetings. Preferences for treatment may be documented on Advance Directives or Medical Orders for Life Sustaining Treatment forms.

Care recipient: A resident receiving nursing home care.

Continued care: Nursing, rehabilitation, social work, and medical care delivered in a nursing home after hospitalization.

Decision-making capacity: Ability to make a coherent, rational decision; determined by a participant's reasoning during conversation and/or by medical record information.

Family member: A person who the patient or resident or LAR defines as family (e.g., a person 18 years of age or older who the LAR determines as the person most involved in the resident's day-to-day care).

Follow-through: Care continuity after transfer from hospital to nursing home that reflects recommendations from a specialty palliative team.

Legally authorized representative (LAR): "An individual or judicial or other body authorized under applicable law to consent on behalf of a prospective subject to the subject's participation in the procedure(s) involved in the research" (U.S. Department of Health and Human Services, 2009).

Medical Orders for Life Sustaining Treatment: A document that describes treatment preferences and that is implemented as a health care–provider order in a health care

setting.

Participant: A person enrolled in the study.

Palliative care: Care delivered across the trajectory of a life-limiting illness that includes the patient/resident and family as the unit of care in symptom management, goals of care, and psychosocial and spiritual support as operationalized by the National Quality Forum (2006). Examples include assessing and managing symptoms (e.g., measuring and treating pain and dyspnea) in a manner acceptable to the resident and family, addressing emotional changes and coping (e.g., identifying and treating anxiety and depression), carrying out advance care planning and/or family meetings (e.g., discussing diagnoses, values, and preferences) to form a plan of care acceptable to the resident/family, and recognizing spiritual and cultural preferences.

Patient: A hospitalized person or a recently hospitalized person who has been discharged.

Resident: A recently hospitalized person admitted to a nursing home or a person who lives in a nursing home.

Organization

The following is a summary of the dissertation's organization. Chapter 2 provides a synthesis of the literature focused on the care of patients discharged to nursing homes following a hospital-based palliative care consult. The chapter is formatted for publication in *Research in Gerontological Nursing*. Chapter 3 is an overview of the research methods for the study. Chapter 4 presents the results of Aim 1—to describe the continuity of a patient's palliative care plan from the hospital to the nursing home; this chapter is formatted for publication in *Journal of the American Geriatrics Society*.

Chapter 5 presents the results of Aim 2—to describe the experience of patients admitted to the nursing home following discharge from a hospital with a palliative care consult. It is formatted for publication in the *Journal of Palliative Medicine.* The dissertation concludes with Chapter 6.

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CHAPTER 2

AN INTEGRATIVE REVIEW OF THE LITERATURE ON HOSPITAL PALLIATIVE CARE TEAMS AND POSTACUTE CARE FOCUSED ON NURSING HOME FACILITIES

Abstract

Although palliative care consultation teams are common in U.S. hospitals, the follow-up and outcomes of consultation for frail older adults discharged to nursing home facilities are unclear. To summarize and critique research on the care of patients discharged to nursing homes following a hospital-based palliative care consult, a systematic search of PubMED, CINAHL, Ageline, and PSYCINFO was conducted in February 2016. Data from the articles (n = 12) were abstracted and analyzed. The results of 12 articles reflecting research conducted in five countries are presented in narrative form. Of the studies, two focused on nurse perceptions only, three described patient/family/caregiver experiences and needs, and seven described patient-focused outcomes. Collectively, these articles demonstrate that disruption in palliative care service upon hospital discharge and nursing home admission may result in high symptom burden, poor communication, and inadequate coordination of care. High mortality was also noted.

Introduction

Palliative care is person-centered care at any point in the illness trajectory to patients with serious or life-limiting disease and their families. Its focus is on pain and symptom management, communication about individual goals of care and treatment choices, and psychological and spiritual support. Palliative care improves quality of life and reduces suffering (National Consensus Project for Quality Palliative Care, 2013; World Health Organization, 2015).

Over the past 15 years, there has been a threefold increase in the number of palliative care teams in inpatient hospital settings; more than 60% of hospitals with 50 beds or more reported presence of a palliative care team (Center to Advance Palliative Care, 2014). Multiple studies have explored the impact of hospital-based palliative care consultation on patient care and outcomes, financial impact, and the patient's and family caregiver's satisfaction with care (Cassel, Webb-Wright, Holmes, Lyckholm, & Smith, 2010; Chand, Gabriel, Wallace, & Nelson, 2013; May, Normand, & Morrison, 2014). Overall, the literature reports favorable outcomes on pain and symptom management, quality of care, hospital costs, and patient and family satisfaction during hospitalization. However, this empirical evidence is limited in that it does not examine the impact on care that is delivered during and after discharge from the hospital.

Care coordination and continuity across settings, including planning for hospital discharge, are considered core components of palliative care (National Consensus Project for Quality Palliative Care, 2013). Preparation for hospital discharge for patients with life-limiting illness is often complex due to the unpredictable illness trajectory, shifting goals of care, and availability of resources to meet patients' needs. Manfredi et al. (2000)

found that their palliative care team contributed to the discharge plan for more than 80% of the patients seen for a palliative care consultation. However, the majority of patients were cared for in the hospital until death, discharged with hospice support, or discharged with outpatient palliative care. The remaining patients were discharged to a nursing home or sent home with home health care. It is unclear whether palliative care resources were available beyond the hospital, especially for frail older adults discharged to nursing homes. Other researchers reported that up to 49% of patients who received a palliative care consult in the hospital underwent discharge to a nursing home facility (Cassel et al., 2010; Ciemins, Blum, Nunley, Lasher, & Newman, 2007; Cowan, 2004; Hanson, Usher, Spragens, & Bernard, 2008). The purpose of this chapter is to present the findings of an integrative literature review that focuses on the care of patients discharged to nursing homes following a hospital-based palliative care consult.

Methods

Search Strategy

MeSH and non-MeSH terms to identify possible articles for inclusion in the review included *palliative, palliative care, palliative medicine, hospital, hospitalization, transfer, discharge, patient transfer, patient discharge, discharge planning, continuity of patient care, nursing home, nursing facility, long-term care, rehabilitation center, skilled nursing facilities,* and *subacute care.* Four electronic databases (PubMED, CINAHL, Ageline, and PSYCINFO) were searched using the following search strategy: “palliative care AND hospital AND discharge [all] AND (nursing home OR nursing facility OR extended care facility).” No limits in dates were applied in order to capture all research.

All English-language articles in the databases as of February 2016 were included. Articles were limited to adults. Because this review integrated data from diverse studies, both experimental and nonexperimental, recommendations from Whittemore & Knafl (2005) guided the review approach. The 27 PRISMA (preferred reporting items for systematic reviews and meta-analyses) recommendations provided additional guidance for this review (Moher, Liberati, Tetzlaff, & Altman, 2009).

Retrieved titles and abstracts were screened for relevance, and individual articles were assessed for inclusion (see Figure 2.1). To be included, a study needed to address inpatient hospital palliative care, illness trajectory after hospital discharge, and/or posthospitalization discharge follow-up involving the nursing facility setting. Additional studies were excluded if authors reported only on tool testing and development, hospital mortality or in-hospital outcomes, hospice outcomes, palliative home care, or home discharge without inclusion of a nursing home. Studies that focused on hospice care were excluded due to the empirical evidence that palliative care outcomes are improved when nursing home residents receive hospice care (Stevenson & Bramson, 2009).

Analysis

Data were abstracted and analyzed systematically and entered into a matrix with the following topics: (a) study year and authors, (b) study location/setting, (c) research question/hypothesis, (d) study design, (e) sample characteristics, (f) results, (g) strengths, (h) limitations, (i) clinical implications, and (j) research implications. Studies were then categorized by sample type: *Provider*, *Patient/Family/Caregiver*, and *Patient*. *Provider* studies included those in which the researchers described nurse perceptions of palliative

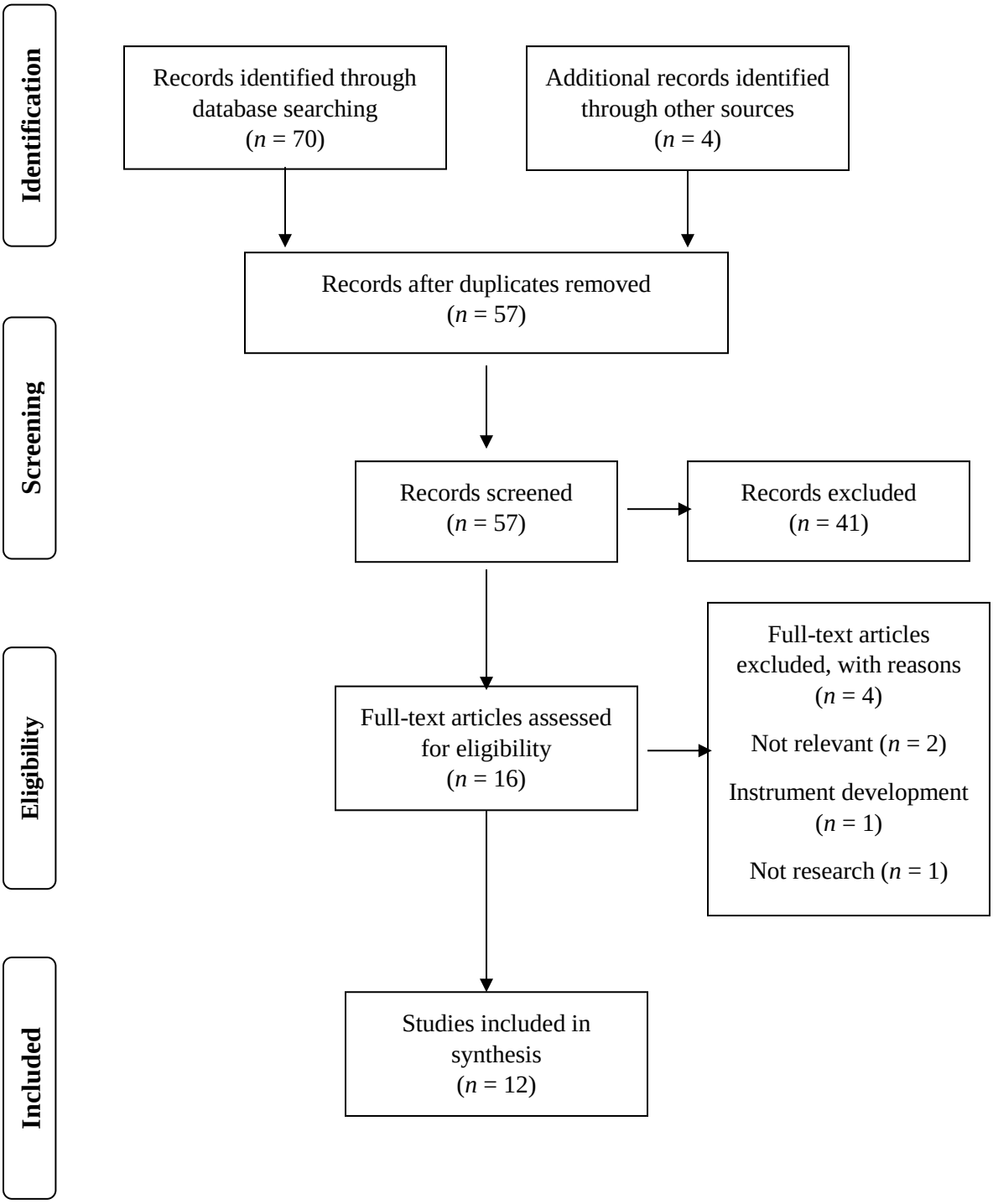

Figure 2.1. Flow Diagram of Article Selection

care patients' needs after hospital discharge and the nurses' role in maintaining continuity in patient care. Data for these studies were collected through focus groups and semistructured interviews. *Patient/Family/Caregiver* studies described outcomes during and after hospitalization of palliative care interventions targeted at family caregivers, determined how palliative care teams could prepare patients for discharge, and established an understanding of the patient/family experience after discharge. Surveys, individual interviews, videos, and medical records provided the data in these studies. *Patient* studies focused strictly on patient outcomes during and after hospitalization and primarily relied on administrative databases and surveys for data collection.

To minimize bias, an iterative approach to analysis with constant comparison techniques to explore patterns and themes was employed. A report maintaining a log of events during data collection and analysis was kept (Whittemore & Knafl, 2005).

Results

The literature review included 12 articles from all searches. This literature reflected research conducted in five countries from 2001 to 2013. Reflecting the recent growth of palliative care research, 10 articles were published between 2010 and 2015. All articles were original research studies or quality improvement reports published in peer-reviewed journals. Table 2.1 details the country of study origin, author, and year of publication.

Methodological approaches varied, although most studies were pilot work or descriptive (Benzar, Hansen, Kneitel, & Fromme, 2011; Blackford & Street, 2001; Catic et al., 2013; Thon Aamodt, Lie, & Helleso, 2013). Three studies were longitudinal over a

Table 2.1. Study Origin, Authors, and Year

Country of Origin	Authors and Year
United States (*n* = 8)	Baldwin et al. (2013); Benzar, Hansen, Kneitel, & Fromme (2011); Brody, Ciemins, Newman, & Harrington (2010); Catic et al. (2013); Enguidanos, Vesper, & Lorenz (2012); Fromme et al. (2006); Gade et al. (2008); Tallman, Greenwald, Reidenouer, & Pantel (2012)
Australia (*n* = 1)	Blackford & Street (2001)
United Kingdom (*n* = 1)	Gerrard et al. (2011)
Germany (*n* = 1)	Kötzsch, Stiel, Heckel, Ostgathe, & Klein (2014)
Norway (*n* = 1)	Thon Aamodt, Lie, & Helleso (2013)

one- to two-year period (Fromme et al., 2006; Kötzsch, Stiel, Heckel, Ostgathe, & Klein, 2014), including one ethnography (Tallman, Greenwald, Reidenouer, & Pantel, 2012). Hospital databases were used to conduct retrospective cohort and matched case control studies (Baldwin et al., 2013; Brody, Ciemins, Newman, & Harrington, 2010; Enguidanos, Vesper, & Lorenz, 2012). One randomized control trial (Gade et al., 2008) and one quality improvement project with repeated measures over a two-year period (Gerrard et al., 2011) were reviewed.

Two studies (both international) focused on nurse perceptions only, three articles (one international) reported patient/family/caregiver-oriented research outcomes, and seven studies (two international) included patient-oriented outcomes only. Four themes across the three sample categories were (a) symptom management (e.g., ability to manage, education, information, unmet needs); (b) communication (e.g., clarity, respecting choices, participation in advance-care planning); (c) care continuity and hospital readmission (e.g., who to contact, timely access to care, care trajectory); and (d) patient survival. Refer to Table 2.2 for additional details.

Table 2.2. Summary Matrix

Sample Type	Authors	Results	Themes
Clinicians			
	Blackford et al., 2001	After discharge, ineffective communication and professional territorialism resulted in poor care continuity and coordination, especially when sent to nursing homes.	Communication Care Continuity & Rehospitalization
	Thon Aamodt et al., 2013	Complexity of patient health status and perceived competency of nurses at discharge destination resulted in reluctance to discharge patients to nursing homes without specialty palliative care.	Symptom Management Care Continuity & Rehospitalization
Patient/Family/Caregivers			
	Benzar et al., 2011	Three main themes related to discharge: 1. Prognosis (vague and unclear information) 2. Symptom management (inadequate preparation to recognize/treat symptoms) 3. Whom to call with questions (knowing who to contact for problems)	Symptom Management Communication Survival
	Catic et al., 2013	During hospitalization, there was a high rate of intravenous treatments, venipunctures, and radiologic exams; however, 86% of patient proxies stated comfort was the goal of care. By one month after hospital discharge, 24.1% of all the patients had died. Intervention group subjects reported better outcomes (greater knowledge, better communication, more advance-care planning, lower rehospitalization, and fewer feeding tube insertions).	Survival Communication Care Continuity & Rehospitalization
	Tallman et al., 2012	Five themes were related to care along the identified illness trajectory but varied in importance: 1. Sensitive, effective communication about advanced illness 2. Timely access to coordinated medical care 3. Respect for and honoring care decisions 4. Psychological, social, and spiritual needs 5. Family caregiver support Needs related to communication, access to medical care, and caregiver support increased up to one year after hospital discharge with a palliative care consult.	Communication Care Continuity & Rehospitalization Symptom Management

Table 2.2. Summary Matrix (continued)

Sample Type	Authors	Results	Themes
Patient			
	Enguidanos et al., 2012	Of all patients discharged after a palliative care consult, 10% were readmitted at 30 days. The top location from which patients were readmitted was the nursing home (34.1%, or 14 of 41 readmissions). Of all patients discharged to nursing homes, 24.1% were readmitted (14 of 58 patients discharged to a nursing facility). Compared with patients discharged with hospice or home palliative care, those discharged to nursing homes were 5 times more likely to be readmitted to the hospital within 30 days of hospital discharge. Suggests that needs are not being met in nursing home.	Care Continuity & Rehospitalization
	Brody et al., 2010	Of patients who died within 30 days of hospital discharge, 42% had received palliative care and were discharged to a skilled nursing home. Of patients who died within 31–90 days of hospital discharge, 20.3% had received palliative care and were discharged to a skilled nursing home. At the end of life, when compared with usual care patients, fewer patients seen by the palliative care team were discharged to a skilled nursing home facility. However, in total, more palliative care patients were initially discharged to nursing homes. Those who received palliative care consults were more likely to receive continued care postdischarge in the form of hospice care. It is unclear if nursing home patients benefited from continued palliative care in this study.	Survival

Table 2.2. Summary Matrix (continued)

Sample Type	Authors	Results	Themes
Patient (continued)			
	Fromme et al., 2006	63% of palliative care patients were discharged alive (183/292). 10% of discharged patients were readmitted within 30 days. 50% of palliative care patients were seen for discharge planning and to clarify goals. 20% were discharged to a nursing home. Of the 70 patients who died 1–14 days after discharge, 18.6% were in a nursing facility (27.1% were at home, 48.6% had inpatient hospice). Of the 59 who died within 15 days to 6 months, 30.5% were in a nursing facility (49.2% were at home, 15.3% had inpatient hospice). Researchers determined categories of patients who need to be identified based on life expectancy: (a) the patient will die in the hospital, (b) the patient will die within two weeks of hospitalization, (c) the patient will die within six months of hospitalization, or (d) the patient has an unknown life expectancy but has a tremendous symptom burden and need for palliative care. This suggests a need for continuity outside of the hospital.	Survival Care Continuity & Rehospitalization
	Baldwin et al., 2013	Of those who were discharged to postacute care, the most common characteristics of palliative care needs were wounds, oxygen use at discharge, chaplain consultation during hospitalization, delirium/dementia, and presence of a do not resuscitate order. Average intensive care length of stay was 5 days; average hospital length of stay was 17 days. Six-month hospital readmission and mortality rate were up to 40%. Only six patients in the sample received palliative care consults during hospitalization. There were no reported outcomes on the six who received consults. Patients with potential unmet palliative care needs were discharged to nursing facilities. No outcomes were reported in the nursing facility.	Survival Symptom Management Care Continuity & Rehospitalization

Table 2.2. Summary Matrix (continued)

Sample Type	Authors	Results	Themes
Patient (continued)			
	Gade et al., 2008	There was no difference in survival after hospital discharge between the palliative care consult patients (median survival = 43.0 days) and the usual care patients (median survival = 43.5 days). Costs of health services in the six months following discharge, including skilled nursing facility admissions for the palliative care group, were lower. There were no reported outcomes specific to nursing facility patients.	Survival Care Continuity & Rehospitalization
	Gerrard et al., 2011	In a two-year span, the percentage of patients who stated the nursing home was their preferred place of care and who went on to die in the nursing home rose from 53% to 100%. Preferred place of care is easier to discuss than preferred place of death. Preferred place of care was noted to change over time: 37% of patients changed their minds of their preferred place of care. This implies a need for continuing communication throughout illness.	Care Continuity & Rehospitalization Communication
	Kötzsch et al., 2014	Survival from time of discharge for all subjects was 51.7 days. Nursing home patients had the lowest mean survival, at 39.8 days. 66.7% of those discharged to nursing homes were considered to have a "stable care trajectory," defined as minimal changes in care setting for nursing home patients.	Survival Care Continuity & Rehospitalization

Symptom Management: Physical, Psychological, Social, and Spiritual Needs

Four studies focused on patients' symptom management needs postdischarge—three of those were qualitative, and one was an observational study. The four together indicated that disruption in palliative care service upon hospital discharge and nursing facility admission was concerning due to inadequate coordination of symptom management interventions between the hospital and nursing home.

The leading concern of inpatient oncology nurses in a Norway hospital planning for patient discharge to a nursing home was the lack of clinical capacity and palliative care experience of the nurses in the receiving facility. The hospital nurses felt that patients should only be discharged to a nursing home when pain was well controlled. If the nursing home had a specialty palliative care unit, hospital nurses perceived better care delivery, especially for older adults with functional limitations, multiple chronic conditions, and fluctuating symptoms (Thon Aamodt et al., 2013).

In two descriptive studies, patients and family caregivers identified concerns about their own ability to identify and relieve symptoms after hospital discharge, even with a palliative care consult that included substantial emphasis on symptom management. Instructions for managing symptoms were not written down, counseling regarding medication dose adjustment did not take place, and new problems with existing symptoms occurred. Despite having access to medical and nursing care, family members reported dissatisfaction with the care their family members received in nursing facilities (Benzar et al., 2011; Tallman et al., 2012).

Baldwin et al. (2013) used proxy measures to identify potential palliative care

needs of older adults discharged for postacute care in nursing homes. Proxy measures were defined as characteristics indicative of palliative care needs (e.g., presence of wounds indicating symptom burden, psychological distress such as delirium, and poor prognosis including advanced cancer) identified by expert input, clinical practice guidelines, and empirical evidence. They found that 88% of the study sample had one or more potential palliative care needs.

The longitudinal study of patients and families greatly expanded observation and reporting of ongoing symptom needs after hospital discharge. Family caregivers reported not only that psychological, social, and spiritual needs are very important during the hospital palliative care consult but also that these needs appear to persist months after discharge. However, when other issues (e.g., pain or dyspnea) were more noticeable, psychological, social, and spiritual needs seemed less important to patients and family caregivers (Tallman et al., 2012). Baldwin et al. (2013) also reported that unmet psychological and spiritual needs are especially prominent in older adults discharged to nursing facilities after an intensive care unit stay during hospitalization.

Communication

Poor communication and unmet needs for information and education in the postdischarge setting were reported as problematic in three studies (Benzar et al., 2011; Blackford & Street, 2001; Tallman et al., 2012). This finding was true even for those patients who had recently left the hospital; some patients and family caregivers did not recall the palliative care team specialists from the hospital consult. In addition, when concerns did arise, there was difficulty in determining the best person to answer a

question due to the complexity of the health care system. In the months following palliative care consults, patients and family caregivers reported that they continued to require information about advanced illness. Two reports described that engaging patients and family caregivers in ongoing communication, education, and advance-care planning may result in clearer expectations and care aligned with preferences (Catic et al., 2013; Gerrard et al., 2011).

In the reviewed studies, communication was reported as very important to nurses, patients, and family caregivers. Ineffective communication with primary care providers of discharged patients negatively impacted care in the nursing home setting (Blackford & Street, 2001). Ineffective communication was reported in the form of delays in discharge summaries or transfer notes making it to the postdischarge setting and lack of detail or full information about the events during hospitalization. "Professional territorialism" (Blackford & Street, 2001, p. 276)—that is, the perception of nurses acting outside of their usual role—weakened lines of communication and resulted in unreturned phone calls and an inability to connect with primary care providers after transition of care.

Tallman et al. (2012) noted in an ethnographic study of 12 cases (approximately 20% of which were discharged to nursing homes) over one year that family caregivers' need for clear communication of information increased in the postdischarge setting. Participants reported that setting clear expectations for disease trajectory and what to expect in the future was important to caregivers during the initial palliative care consult. Interruptions in care continuity after discharge were primarily related to how to initiate communication about a new or recurrent issue or symptom, especially for those patients not using hospice care (Benzar et al., 2011; Tallman et al., 2012).

Palliative care team communication and goals-of-care discussions included asking patients where they want to receive care in the postdischarge period; for some patients with life-limiting illness, this might be the preferred place of care until death. Gerrard et al. (2011) described their U.K. health care system's palliative care team's effort to meet patient requests to remain in their preferred place of care until death. In this report, the stated preferred place of care at discharge was also defined as the preferred place of death for terminally ill patients. Over a two-year period (2007–2009), the percentage of match between the nursing home as the stated preferred place of care and nursing home death increased from 53% to 100%. However, the study did not reference where goals were documented and how these outcomes were achieved, thus limiting its usefulness.

A pilot study in the United States that targeted communication, education, and follow-up with family caregivers/proxy decision makers of people with dementia resulted in greater reported communication and advance-care planning discussions at one month postdischarge (Catic et al., 2013). A key component of this intervention provided specific follow-up with the family caregiver/proxy decision maker two weeks after discharge to review health status, goals and decision making, and need for information. Detailed information about the palliative care consult was also sent to the patient's primary care provider.

Care Continuity and Hospital Readmission

In whole, 10 study findings suggested that continuity of care hinges on regular, interactive dialogue among patients, family caregivers, and health care providers throughout the course of illness. Those studies without palliative care follow-through

after hospitalization reported care discontinuity and hospital readmission. Researchers who noted lower hospital readmission rates for palliative care patients and more stable care trajectories, including death in the preferred place of care, cited the discharge planning process and continual interaction as the reasons for improved outcomes.

In the posthospital period, nurses and family caregivers of patients who received palliative care during hospitalization reported greater use of medical services when new symptoms required a change in the plan of care. Often, frequent visits to the emergency department and subsequent rehospitalization occurred for acute changes that needed immediate resolution (Tallman et al., 2012; Thon Aamodt et al., 2013). Acute care nurses in Norway anticipated rehospitalization for patients' symptoms that could not be managed in a nursing home (Thon Aamodt et al., 2013).

Enguidanos et al. (2012) observed that of all patients who received palliative care consults and were discharged to nursing homes, 24% were readmitted at one month. In addition, when compared to patients discharged with hospice or home palliative care, patients discharged to nursing homes were 5 times more likely to be readmitted to the hospital within 30 days of hospital discharge. Baldwin et al. (2013) showed that 37% of the sample with potential palliative care needs were readmitted to the hospital from nursing homes at six months (approximately 20% of the sample lived in a nursing home before hospital intensive care admission). Fromme et al. (2006) found that only 10% of their sample was readmitted at one month; however, it is not clear what proportion of these patients were discharged to and readmitted from nursing homes (20% of the entire sample transferred to a nursing home after hospitalization). Despite high hospital readmission rates for palliative care patients, when compared to those receiving usual

care, researchers reported that costs were overall reduced, including for those in a skilled nursing facility after palliative care consult during hospitalization (Gade et al., 2008). It is unclear whether reduced costs were associated with lower hospital readmission rates in this sample.

U.S. researchers found a lower hospital readmission rate at one month after discharge with a palliative care education and support intervention for family caregivers of people with dementia, the majority of whom lived in nursing homes (Catic et al., 2013). A key part of the intervention included postdischarge support and contact with the primary care provider. However, this pilot study was not adequately powered to generalize results. Gerrard at al. (2011) also showed that in the United Kingdom, continuing care until death in the preferred place is achievable when patients are asked about their preferences, although preferred place of care and death is subject to change over time as an illness progresses.

Care continuity for nursing home residents was also reported by a research team in Germany (Kötzsch et al., 2014). Patients discharged to nursing homes had the most stable care trajectory, second only to those in hospice care. Almost half of the discharged patients in the entire sample were followed by a specialized outpatient palliative care team. Australian palliative care nurse consultants reported good continuity of care when they were able to participate in the discharge planning process, provide clear information to the postacute care setting about the hospitalization, and follow up after discharge (Blackford & Street, 2001).

Survival

Seven reports included survival after palliative care consult as an outcome. Overall, survival in the nursing home after palliative care during hospitalization is poor. Two studies conducted in Germany and the United States were unique in that they reported survival with different models of palliative care services available in the nursing home (Catic et al., 2013; Kötzsch et al., 2014). The other five articles only reported survival after hospital discharge; it is unknown if and how palliative care was delivered to those patients.

Several U.S. research teams have investigated the outcomes of palliative care on discharge disposition and survival. When separating out patients who died within 30 days of a palliative care consult and hospital discharge, Brody et al. (2010) reported that 42.0% of those who died were discharged to a nursing home. Of those who died one to three months after palliative care consult and discharge, 20.3% were discharged to a nursing home. Another U.S.-based research team reported that at six months after palliative care consult and hospital discharge, 24.0% of all deaths occurred in a nursing home facility (Fromme et al., 2006). In comparison, 33.3% of the sample was discharged to inpatient hospice and 37.2% to a personal home, with the majority having hospice support.

Kötzsch et al. (2014) reported that posthospital survival was lowest (39.8 days) for patients discharged to nursing homes who received palliative care during and after hospitalization as compared with all patients (51.7 days). However, it is unclear how palliative care services were organized and delivered and how many study participants received the services. Of those with palliative care needs in the intensive care unit during

hospitalization and discharged to a nursing facility, 40% had died at six months (Baldwin et al., 2013).

In a study to ascertain outcomes of patients who received inpatient palliative care, Fromme et al. (2006) noted several categories of patients that could be identified based on life expectancy. Of the 70 patients who died 1–14 days after discharge, close to 20% were in a nursing home; of the 59 patients who died 15 days to 6 months after discharge, 30% were in a nursing home. Based on their findings, the authors suggested that assigning the following life expectancy categories can lead to more efficient discharge planning: (a) if the patient will die in the hospital, (b) if the patient will die within two weeks of hospitalization, (c) if the patient will die within six months of hospitalization, and (d) if the patient has an unknown life expectancy but has a symptom burden.

Discussion

Most concerning in this review is that despite having access to medical and nursing staff in nursing homes, patients and families still feel that symptoms may not be adequately managed. Symptoms such as pain and dyspnea can be challenging to manage and may cause fear and anxiety for patients and family caregivers. Pain and other symptoms may be related to a patient's spiritual and psychosocial issues at end of life in addition to the physical experience (e.g., total pain). Some researchers reported that nursing home staff lacked skill in end-of-life care and therefore could have difficulty assessing and managing complex symptoms (Unroe, Cagle, Lane, Callahan, & Miller, 2015). Cognitive impairment inhibits verbal and nonverbal assessment of nursing home residents' pain, and nurses may feel unsure about analgesic safety and use (Burns &

McIlfatrick, 2015; Monroe, Carter, Feldt, Tolley, & Cowan, 2012). It is unclear how symptoms are being managed after hospitalization for these patients. For this reason, additional in-depth systematic study of symptom management, psychosocial support for anxiety and depression, and spiritual care in the nursing facility setting are needed.

Communication is the cornerstone of palliative care. This review demonstrates that advance-care planning conversations (about prognosis, goals, and care preferences) and the logistics of when and how to contact palliative care specialists are important for nurses, patients, and family caregivers alike. Discussions about prognosis need to be clear and concise to help patients and family caregivers decide if a nursing home is the best place after hospitalization to care for patients with serious or life-limiting illness. Extensive and complete discharge planning with postdischarge support of palliative care patients is needed to maintain care continuity (King et al., 2013) and reduce rehospitalization when symptoms worsen, new symptoms develop, or goals of care change (Meier & Beresford, 2008).

Advance-care planning conversations lead to better outcomes and high-quality care that is consistent with the patient's and family's goals (Bernacki & Block, 2014). None of the research in this synthesis describes how well palliative care teams match expressed goals of care and actual care delivery in a comprehensive manner. Only one team (the quality improvement project) reported patient preferred place of care and death; however, they were limited to reporting outcomes that were not scientifically investigated (Gerrard et al., 2011).

Additional topics around communication, care continuity, and rehospitalization worthy of investigation include the following: What is the continuity of patients'

palliative plan of care from the hospital to the nursing facility? How do patients perceive care delivery after goals are elicited? What causes palliative care patient readmission, and how can rehospitalization be limited to those that are concordant with patient and family care preferences? What community-based palliative care services are available for nursing home residents?

It is concerning that when compared to those discharged to personal homes, mortality is higher for those discharged to nursing facilities. This finding may be because patients who are discharged to nursing facilities are relatively sicker and may be closer to death than those discharged to personal homes. Patients are often admitted to nursing facilities for nursing and rehabilitative care to improve or stabilize their overall condition. In this context, patients' and family caregivers' confusion may grow about goals of care in serious life-threatening illness when improvement is not realistic. In addition, the barriers to providing palliative care in U.S. nursing homes have been widely documented. These challenges include regulatory and economic issues (specifically reimbursement policy), staff education and training, the facility culture, and lack of administrative support and leadership (Center to Advance Palliative Care, 2008). Additional research is needed to determine how well nursing home facilities are able to implement hospital palliative care recommendations into nursing and rehabilitative care. Remaining questions include the following: How are hospital palliative care teams and nursing facilities aligning goals with care? How do patients and/or families perceive adherence to goals of care after hospital discharge with a palliative care consult?

Implications for Future Research

The majority of the reviewed studies were descriptive, observational, and exploratory. One experimental randomized controlled trial looked primarily at costs after discharge and did not separate outcomes of patients discharged to nursing facilities. Authors who used cross-sectional retrospective designs on large administrative databases reported findings limited to survival and likelihood of hospice admission. A strength of this reviewed literature, however, is that several researchers focused on in-depth individual experiences. Comprehensive study of personal perspectives, through interviews, medical record reviews, and longitudinal designs, allowed for reporting person-focused outcomes—in one instance, up to two years after a palliative care consult.

Synthesizing a body of literature of palliative care and nursing facility research conducted in different countries using various methods is challenging. The first major issue encountered while analyzing this research was that inpatient and outpatient palliative care are defined, managed, and delivered differently internationally. For example, health care professionals in Norway follow formal recommendations for generalist palliative care, specialist palliative care, and a palliative care "approach" in primary care. For the most part, palliative care is widely available, community-based care that is delivered in the home environment (Thon Aamodt et al., 2013). The second factor was that nursing homes do not deliver palliative care uniformly from country to country. In Germany, palliative care is considered a health care right, and palliative care principles are integrated into nursing homes, where patients are expected to live until they die (Kötzsch et al., 2014). The findings of international literature are of limited use in the United States because of different reimbursement structures and health care systems. In

addition, palliative care is not defined, operationalized, or paid for in the same way.

However, gleaning knowledge from international research can shape the development and advancement of palliative care research in the United States. For example, the international literature had less emphasis on studying survival. Instead, research teams focused on studying care continuity (Kötzsch et al., 2014), clinician perceptions (Blackford & Street, 2001; Thon Aamodt et al., 2013), and patient preferences (Gerrard et al., 2011).

Two implications of this review include a need for studying how well pain and symptoms are managed and how promptly prognoses and goals of care are readdressed after hospital discharge. Longitudinal systematic study of how well palliative care teams are able to match a patient's care to his or her care preferences is needed. Prospective person-level narratives or case studies of individual preferences and care follow-through would allow for a better understanding of these outcomes.

For health care providers, a better understanding of the benefits of clear, concise communication during discharge planning is needed. Clinicians should consider a patient's symptom burden and functional status (e.g., ability to carry out daily living activities) as a predictor of survival and should integrate this information into discussions when planning for hospital discharge and continued care.

Conclusion

There is no available systematic study on how palliative care teams are managing posthospital transitions and care for patients discharged to nursing facilities. The findings of this review demonstrate a deficiency in understanding the posthospital experience after

a palliative care consult. The literature does not describe integration and follow-through of palliative care after hospitalization, including whether recommendations are implemented and followed in the nursing home. Multiple studies have shown that palliative care improves care satisfaction during hospitalization and does not reduce survival when compared to a patient receiving usual care. Empirical study of palliative care in nursing homes after hospitalization is needed to determine whether similar outcomes are attainable.

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CHAPTER 3

METHODS

Introduction

The purpose of this qualitative descriptive study was to describe the follow-through of palliative care after nursing home admission and of resident outcomes in the nursing home after a palliative care consult during hospitalization. The investigator posited that through semistructured interviews to gain participants' perspectives and a review of medical charts describing resident care, this study would improve understanding of posthospital palliative care delivery in U.S. nursing homes. This study addressed the following aims and research questions (RQs):

Aim 1) Describe the continuity of a patient's palliative care plan from the hospital to the nursing home.

RQ 1: What palliative care recommendations made during hospital palliative care consult are followed through and received by residents in the nursing home?

Aim 2) Describe the experience of patients admitted to the nursing home following discharge from a hospital with a palliative care consult**.**

RQ2: What are the immediate and long-term outcomes (e.g., goals of care, advance-care planning, symptom management, psychosocial support, spiritual care, nursing, rehabilitation, medical care) for residents in the nursing home after a palliative care

consult during hospitalization?

RQ3: How do patients and/or families perceive pain and symptom management, adherence to goals of care, and psychosocial support in nursing homes after hospital discharge with a palliative care consult?

This chapter provides the framework for the study methodology. The main topics are as follows: (a) an overview of the study design, (b) a description of the study setting and sample, (c) data collection procedures, (d) data analysis, (e) issues of qualitative rigor and bias, (f) potential challenges and study limitations, and (g) ethical considerations and protection of human subjects. A summary concludes the chapter.

Design

A qualitative approach to this research described the process that occurred for study participants, their points of view, and their experiences of care. The goal of qualitative descriptive research is to report the details and experiences of the participants, including the commonalities and differences, and to explain a phenomenon when little is known (Bernard & Ryan, 2010; Sandelowski, 2000, 2010). The investigator used the data for description, instead of transforming data to inform theory or interpret culture (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2010). This study was designed to investigate experiences of only those who received a consult with a palliative care team. The assumption in a referral and consultation is that the patient has unmet needs requiring palliative care services beyond generalist-level palliative care provided by an attending or primary care provider (Weissman & Meier, 2011). For this understudied phenomenon, description is the natural starting point for developing an

empirical foundation that provides data for additional research questions and systematic study (Thorne, 2008).

Interviews were combined with chart review data to elucidate the larger context of continuity of palliative care, resident perceptions and experiences, and clinical outcomes (Bernard & Ryan, 2010; National Quality Forum, 2006). Interviews were completed with participants who could take part in a conversation. For enrolled residents unable to participate in a conversation, an eligible participant's legally authorized representative (LAR) was approached for consent and participation in the interviews.

Setting

This study involved the use of two settings, one hospital and one nursing home, located in the mid-Atlantic United States. The hospital is a level III trauma center that has an active inpatient palliative care team in the hospital five days each week. One nursing home was identified as the most frequent location of patient discharge after palliative care consult at the hospital. The nursing home is a 305-bed, for-profit facility, not located within a hospital; it accepts Medicare and Medicaid, provides skilled nursing care, and contracts with a hospice agency. One hospice agency serves both the hospital and the nursing home. The administrators in the two settings were supportive of the study being carried out in their respective facilities. The investigator had, and continues to have, a positive and collaborative professional relationship with the clinical, administrative, and medical staff of both facilities and the hospice agency.

The location of the nursing home and the skilled nursing facility (SNF) benefit use in the study city were reflective of national and state trends (Dartmouth Institute for

Health Policy and Clinical Practice, 2012). At the time of the study, no strategies or models of care in this geographic area combined the SNF benefit with hospice or palliative care, further demonstrating the need to determine follow-through of palliative care and the resident's and/or family member's perceptions of care.

Sample

Purposive criterion sampling used in this study involved selecting participants based on predetermined criteria. Criteria included patients who received a palliative care consult during hospitalization who then received a plan for discharge to a nursing home for continued care without hospice. Each month in the year prior to the study, the palliative care team consistently discharged 5–18 (mean and median: 13) patients to nursing homes without hospice coordinating the plan of care upon admission. In fiscal year 2013, 161 of the 594 patients seen for a palliative care consultation in the hospital were discharged to nursing homes without hospice or without a plan for outpatient palliative care upon nursing home admission. Patients enrolled in hospice care at hospital discharge were excluded from the study because of empirical evidence that better palliative care outcomes are achieved when nursing home residents receive hospice care (Miller, Lima, & Mitchell, 2012).

Participant recruitment started with patients who received a palliative care consult at the participating hospital. Participants who met study enrollment criteria were recruited on a continual basis. After a review of hospital palliative care team data, discharge locations, discussions with the team social worker, and a review of hospital admissions with the nursing facility administrators, the estimated time needed for recruitment of

participants to the identified nursing home was one year. In fiscal year 2013, about half of the palliative care patients discharged to nursing homes could not participate in a conversation about their goals of care. This finding is consistent with past research that reported that up to 70% of persons with advanced dementia—a serious and life-limiting illness—will reside and eventually die in nursing homes (Mitchell, Teno, Miller, & Mor, 2005). Therefore, it was expected that some participants would not be able to consent for themselves nor would they be able to participate in interviews.

The target sample size in this study was 30; however, after data collection and preliminary analysis, sample size was guided by information power (Malterud, Siersma, & Guassora, 2015; Sandelowski, 1995). Using information power, initial data analysis was examined for high-quality data representing variability of participant experiences. When data were found to be abundant and powerful in answering the research questions within and across participant cases, participant enrollment ceased. However, data collection continued until 100 days after the last participant was enrolled.

Patients' decision-making capacity and ability to participate in a conversation were determined by information in the medical record and confirmed by a palliative care team member in the hospital or by a nursing home staff member. When the patient lacked decision-making capacity and was unable to participate in an interview, the LAR was invited to participate in the interviews (Figure 3.1). If the LAR refused patient participation, the patient was not enrolled. If the LAR consented for patient participation but determined that another person 18 years of age or older was more appropriate to participate in the interviews, consent for study patient participation was obtained, and the designated family member was contacted for interview participation.

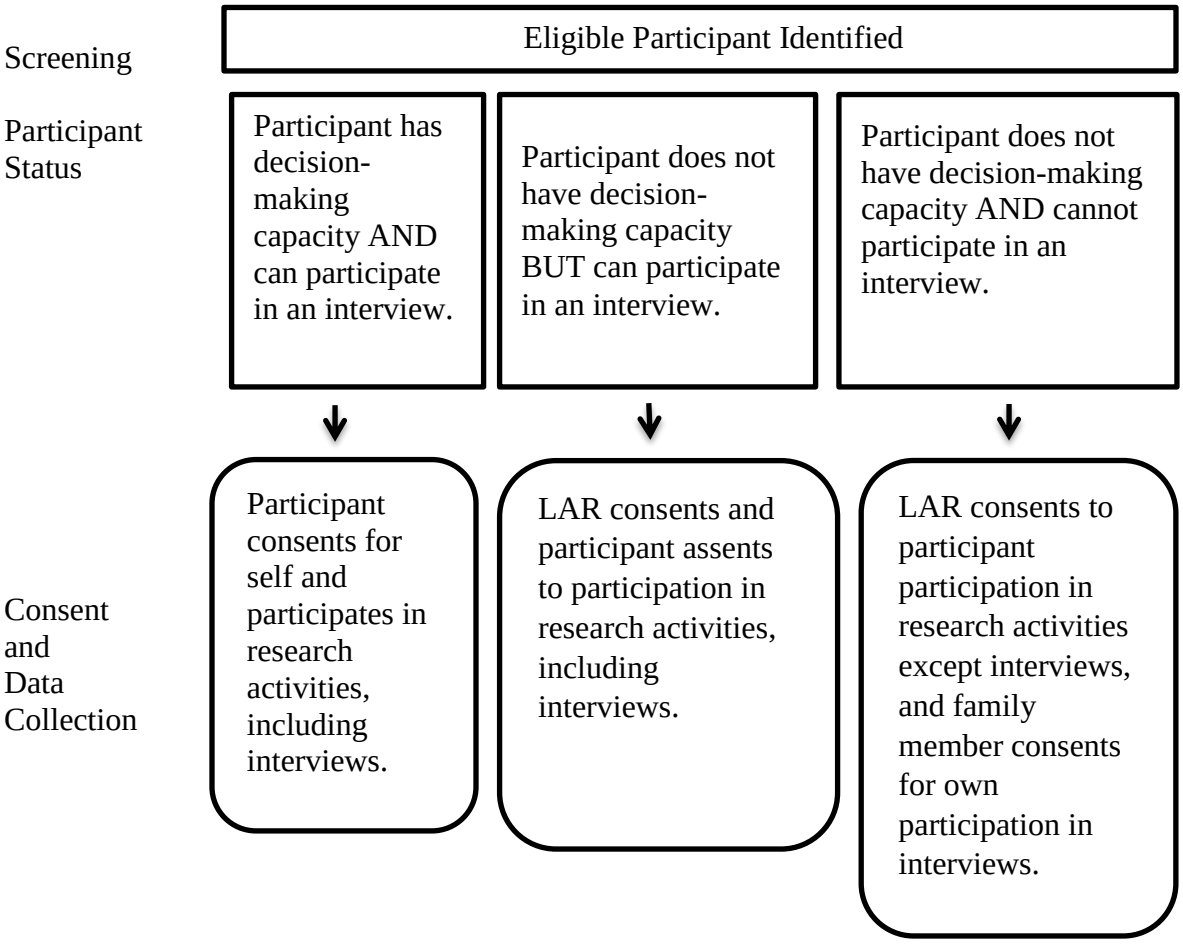

Figure 3.1. Decision Tree to Determine Consent, Assent, and Interview Participation. *Note:* LAR, legally authorized representative.

If a participant's decision-making capacity became compromised, as recorded in the medical record or upon assessment of continued consent by the investigator, the LAR was contacted for consent to continue interviews in the study. If a participant lost the ability to participate in the interviews, the reason was recorded, and interviews were completed as scheduled with the LAR. If resident participants declined participation in the interview, they were asked whether the investigator could reapproach the next day. In either case, chart reviews continued unless the participant or LAR declined further study participation and requested disenrollment. No participants withdrew from the study.

According to law in the state where the study was conducted, if a person lacks health care decision-making capacity and has not appointed a health care agent, a surrogate may make health care decisions in the following priority order by "class": (a) a guardian, if one is appointed; (b) the patient's spouse or domestic partner; (c) the patient's adult child; (d) the patient's parent; (e) the patient's adult sibling; or (f) the patient's friend or other relative. If there is a dispute among surrogates in a class, the dispute should be referred to a patient care advisory committee (Ballard, 2015).

Interviews with participants were completed following a three-step process:

1. Prior to each interview, confirm the participant's ability and willingness to continue with the study.
2. Rely on the nursing home staff's clinical expertise to ensure that the resident could participate.
3. Discontinue the interview if the participant became fatigued or unable to answer questions.

For interview participants who were not nursing home residents, their ability to participate was determined by asking whether they could have a 20-min interview in addition to explain their understanding of the research.

The following inclusion criteria were used for patient participant in chart reviews and interviews:

- The patient received a hospital palliative care consult at the participating hospital.
- The patient received a discharge plan to a participating nursing home.
- The patient is 60 years of age or older.
- The patient has decision-making capacity or an identified LAR.

- The patient is able to speak and understand English.
- The patient is able to participate in a 20-min interview upon admission to the nursing home.
- The patient has a life expectancy of at least 7 days, as determined by the palliative care team.

The following inclusion criteria were used for LAR or family member participation in interviews:

- Resident participant is unable to participate in the interview.
- LAR/family member is able to speak and understand English.
- LAR/family member is able to participate in a 20-min interview upon the patient participant's admission to the nursing home.

Patients who were currently receiving hospice care or who had a plan to transition to the nursing home with hospice care on admission were excluded.

Data Collection

After receiving University of Utah Institutional Review Board approval (including a request for waiver of Health Insurance Portability and Accountability Act (HIPAA) authorization for research, allowing the investigator to screen the charts of potential participants), as well as necessary approvals from the participating hospital and nursing home, the investigator screened clinical records of hospitalized patients who had received a consult by the palliative care team. When a patient met study criteria, a palliative care team member or the investigator asked to inform the patient or LAR about the study. If the patient or LAR agreed, the investigator introduced the study and obtained

informed consent. Data were collected from multiple sources. Figure 3.2 outlines the data collection time points and procedures. One data collection method (chart review) was used at the hospital, and two data collection methods (chart review and semistructured interview) were used at the nursing home.

Chart review data were used to describe what palliative care recommendations made during hospital palliative care consult were followed through and received by residents in the nursing home. They were also used to describe the immediate and long-term outcomes (e.g., goals of care, advance-care planning, symptom assessment and management, psychosocial support, spiritual care interventions such as pastoral care, nursing, rehabilitation, medical care) in the nursing home. Charts were reviewed in the hospital, at nursing home admission, within 7 days of admission, and at 21–30 days and 100 days after admission. The hospital chart was reviewed for date of birth, ethnicity, race, medical diagnoses, medications, advance-care planning, and details of the hospital palliative plan of care. The nursing home chart was reviewed to determine pain and symptom management assessment, interventions, and outcomes; psychosocial and spiritual support; advance-care planning conversations; goals-of-care, family meeting, and care planning discussions and outcomes; and nursing, medical, and rehabilitation care. Advance-care planning was defined as care that was organized (e.g., planned and decided upon) by eliciting values and preferences for future treatments, primarily through a series of meetings. Charts were reviewed for documentation of meetings with the patient or resident and family members or LARs. In addition, presence and content of Advance Directives and/or Medical Orders for Life Sustaining Treatment forms were considered advance-care planning.

	Time Point				
	1	2	3	4	5
Location and Timing of Activities	Study enrollment at hospital	24–48 hrs after nursing home admission	Within 7 days of nursing home admission	21–30 days after nursing home admission	100 days after nursing home admission
Data Collection	Chart review	Chart review	Chart review and semistructured interview	Chart review and semistructured interview	Chart review and disposition status

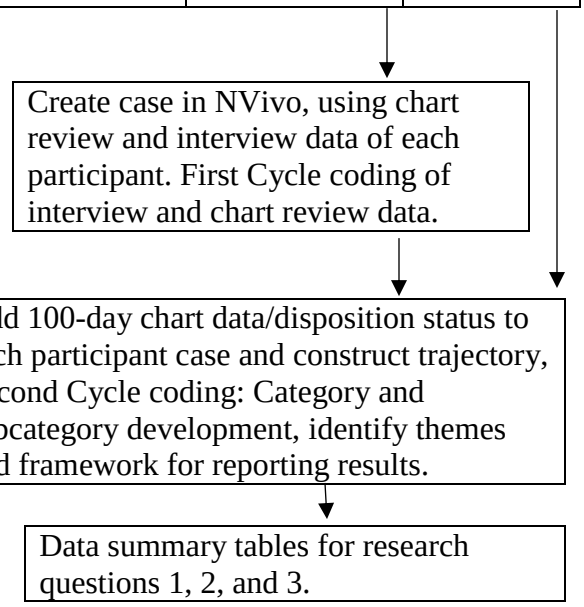

Figure 3.2. Data Collection Time Points and Procedures

Patient status at 100 days, which was essential for constructing the trajectory of the nursing home stay, included discharge disposition and health care use, including hospitalization. Chart audit tools are included in the Appendix.

Semistructured interviews were used to describe patient and/or family perceptions of pain and symptom management, adherence to goals of care (e.g., preferences for treatment, such as not using artificial life support), and psychosocial support in nursing homes after hospital discharge with a palliative care consult. The first semistructured

interview occurred within 7 days of nursing home admission, and the second interview occurred between 21 and 30 days after admission. The interview topics included pain and symptom management at the facility, goals of care, and perceptions of care delivery. Interview guides were also designed to reflect current practices in palliative care (National Quality Forum, 2006) and sensitivity given that participants were seriously ill.

The data collection time points after nursing home admission were chosen based on the following:

- Within 7 days, a plan of care is in place and the resident is "settled" in.
- Between 21 and 30 days, disposition is discussed, and a care planning meeting has occurred.
- At 100 days, the disposition status can be determined.

Interview questions were designed to reflect preferred practices in palliative care (National Quality Forum, 2006). Final interview guides were pilot tested and modified with the committee's guidance and are included in the Appendix. Interviews were audio recorded and transcribed by a professional transcription service, with nonverbal pauses and emotional expressions (e.g., laughing, crying) retained in the transcript. Strategies that protected participants from harm are outlined in the Protection of Human Subjects section of this chapter.

Data Analysis

Chart Reviews and Interviews

De-identified chart review data and transcribed interviews were organized in NVivo v9 according to participant number. The investigator constructed each

participant's data as an individual "case" reflecting data collected from the completed time points in the study. Each case comprised up to five chart reviews and two transcribed interviews, which represented the trajectory from the hospital palliative care consult to up to 100 days after nursing home admission. The investigator verified accuracy of interview transcripts by reviewing each audio recording and the complete word-processed transcript.

At 21–30 days after nursing home admission, data collected for each participant case included up to two semistructured interviews and four chart reviews. This was considered time point four, at which time data analysis began (see Figure 3.2). When a participant was discharged from the nursing home, hospitalized, or died prior to time point four, data analysis began as soon as possible after completion of the last time point.

Inductive content analysis (Elo & Kyngas, 2008) using systematic steps with First and Second Cycle coding methods (Saldana, 2009) was completed with NVivo v9 software. The investigator used content from 11 of the 38 National Quality Forum (2006) preferred practices to develop sensitizing concepts during analysis; however, in keeping with the inductive analytic approach, codes and categories originated from the data. Sensitizing concepts are defined as representations of an abstract idea or notion informed by existing literature (Schwandt, 2007) that provide guidance for data analysis and study reference. In this study, sensitizing concepts were also used in final analysis to confirm theme relevance to preferred palliative care practices.

Coding

First Cycle Coding

First Cycle coding is a primary step in examining qualitative data. The investigator breaks apart the data line by line to identify codes reflective of content. In Vivo coding was used for the First Cycle data coding method (Saldana, 2009) in order to remain close to the data; codes are participants' words or phrases (Neergaard et al., 2009). Another approach that was also suitable for data analysis to meet the study aims during First Cycle coding was Descriptive coding. This additional First Cycle coding method allowed for deeper representation. It is not uncommon during qualitative data analysis to learn that additional coding methods may produce more meaningful findings compared with the original one(s) chosen (Saldana, 2009). In keeping with the person-centered approach and to describe the person-centered perspective of care delivery in the nursing home after discharge from the hospital with a palliative care consult, interview transcripts were coded first line by line in short phrases, with codes reflecting participants' language.

To describe not only the continuity of a patient's palliative care plan from the hospital to the nursing home but also the experience of patients admitted to the nursing home following hospital discharge with a palliative care consult, chart reviews were coded with In Vivo and Descriptive codes.

Additional participant interviews and chart review data either were coded using codes from previous cases or were assigned new codes reflective of the individual participant. The investigator maintained a log of codes, code descriptions, and analytic memos in a codebook. Analytic memos supplied the investigator with self-reflections

during previous coding and supported organization and classification of the codes during Second Cycle coding (Saldana, 2009).

Second Cycle Coding

Second Cycle coding is an additional coding method that sorts and consolidates initial coding (Saldana, 2009). After First Cycle coding was completed on all cases, Pattern coding was used in Second Cycle coding to organize and integrate the large number of phrases from the coded interviews and chart reviews into common categories and themes (Miles & Huberman, 1994). Pattern coding identifies common and meaningful themes, relationships, and explanations in data (Saldana, 2009). Second Cycle coded data were placed in categories and subcategories, as reflected by words or a short phrase that fully and clearly labeled the classified data. Analytic memos made and filed during First and Second Cycle data coding guided the iterative coding process, which included adding time point five during First Cycle coding (100 days after nursing home admission) to the case and coding as detailed under the discussion of First Cycle coding. Analysis continued within and between participants, using the trajectory of each longitudinal case, and overarching themes were identified. This process is detailed in the next section.

Integrating Data Coding and Analysis

To achieve Aim 1—to describe the continuity of a patient's palliative care plan from the hospital to the nursing home—a trajectory from hospital discharge and nursing home admission to discharge/disposition was constructed for each case based on chart

review data. Reflective analytic notes were embedded in the trajectory matrices; coded interview text was linked to trajectories to expand and add details to the care trajectory. Next, the analysis was guided by Pattern coding methods; the investigator compared similarities and differences of coded interview data and each case longitudinally (e.g., trajectory) and identified overarching categories. The categories were examined and defined by features of the coded data. Then the categories were compared using matrices; relationships within and between the categories were identified for core variable(s) reflecting follow-through of palliative care consultation. Categories were then grouped by properties to develop themes. For example, characteristics such as discontinuity/inconsistency and communication breakdown were identified in the categories of "hospital palliative care team plan," "nursing home admission plan," "hospital to nursing home care," and "goal." Together, these categories were grouped in the theme of Goal Discontinuity.

To achieve Aim 2—to describe the experience of patients admitted to the nursing home following discharge from a hospital with a palliative care consult—analysis was guided by comparing care trajectory matrices that chronologically constructed care over the 100-day study period. The matrices were detailed graphical representation of days 1–100 and corresponding events (e.g., symptoms and medical care such as primary care provider visits, emergency department visits, hospitalization, discharge, and death). These matrices were used to develop a collective representation of the longitudinal care experience.

Participants' care trajectory matrices were examined individually, and common trajectories were grouped using Pattern coding. Typologies that described the features of

common care experiences were identified. Various dimensions of each typology were examined using data summary tables that organized each identified typology, categories, and corresponding participants' coded data and outcomes. For example, few symptoms, comfort, and death in facility were categories within the *Comfort Care Continuity* typology. Coded interview responses corresponding to participant typologies were also entered into a data summary table to examine participant and/or LAR perceptions of symptom management, goals of care, and psychosocial support, allowing for further examination of data subsets according to typology.

Data summary tables were constructed for each research question; each table contained identified themes, interview excerpts, and chart review documents that detailed the content of the theme and raw data (participant quotes, field notes, chart data) representative of the theme. During data analysis, the investigator met weekly with the dissertation chair and other committee members as needed to review data coding, categories, and themes.

Final analysis was guided by the National Quality Forum *National Framework and Preferred Practices for Palliative and Hospice Care Quality* guidelines and compared to the identified categories and/or subcategories during Pattern coding. The following National Quality Forum (2006) practices were considered as sensitizing concepts:

1. Formulate, utilize, and regularly review a timely care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals, and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and

externally, to all professionals involved in the patient's care.

2. Ensure that upon transfer between healthcare settings, there is timely and thorough communication of the patient's goals, preferences, values, and clinical information so that continuity of care and seamless follow-up are assured.
3. Healthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.
4. Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.
5. Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.
6. Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
7. Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.
8. Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
9. Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, to

discuss goals of care, disease prognosis, and advance care planning, and to offer support.

10. Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.
11. Provide information about the availability of spiritual care services, and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships. (pp. VII–VIII)[1]

Qualitative Rigor

Throughout analysis, the investigator compared and related data collected from interviews and chart reviews, searching for consistency and closely noting dissonance (Farmer, Robinson, Elliott, & Eyles, 2006). To maintain dependability and, in turn, to accurately reflect participant experiences, data were collected over a prolonged period or 100 days. Data collection with interviews and chart reviews, in addition to analysis of each participant as a "case," provided credibility with methodological triangulation (Farmer et al., 2006). An expectation in using methodological triangulation is that a combination of data sources will confirm findings and complete descriptions better than one data source alone. The triangulation protocol, guided by Farmer at al. (2006), included comparisons between different methods of data collection (chart review and semistructured interviews) and themes during analysis.

Maintaining consistency and reliability of the measurements in data collection

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and analysis was achieved with one investigator collecting data. The longitudinal nature of data collection in this study used prolonged engagement as another tool to improve trustworthiness, as longer time spent collecting data is thought to lead to greater understanding of a research problem (Roulston, 2010). The investigator maintained an audit trail, field notes, and memos contributing to dependability and transferability. The audit trail contains records, notes, and information about managing and conducting the study (Schwandt, 2007). The dissertation chair reviewed notes and memos during data collection, coding, and analysis to enhance trustworthiness. The study was conducted, including the documentation of decisions, with the expectation that other investigators could realistically implement the same study in another sample of participants.

Strategies to Diminish Bias

To control for bias and maintain credibility, the investigator described experiences and reflections in extensive postinterview field notes, journaling, and a log of events kept during data collection and analysis. Practicing reflexivity with written thoughts in a separate journal (study diary) before, during, and after interviews improved validity during the study. Acknowledging assumptions about participants and situations during interviews (Creswell, 2013) assisted the investigator with maintaining trustworthiness of the data.

Consistency checks (e.g., comparing results of the findings from similar research) of the data were not achievable, because limited research exists on the process of care delivery of patients admitted to a nursing home after discharge from a hospital with a palliative care consult. Debriefing and reflexive dialogue (e.g., verbal feedback provided

after reflective thinking and open conversation between researchers about the topic under study) through discussion of beliefs, values, and assumptions helped to prevent imposing preexisting views on data and to reduce bias (Creswell, 2013). Table 3.1 outlines strategies used to diminish bias and enhance trustworthiness.

Alterations in Methods

Challenges to attrition and recruitment resulted in altering study procedures and obtaining Institutional Review Board approval through amendments. Amendments permitted interviews to occur outside of a data collection window, with the LAR after a participant's death, or at the participant's personal residence after nursing facility discharge. Due to the fast pace of hospital discharge, amendments were sought and approved allowing consent to occur 48 hr after hospital discharge (prior to any data collection) and in the location of the LAR's choosing so that enough time was allotted to make a decision about participation.

Ethical Considerations

The investigator is a member of the hospital palliative care team but did not consult or treat inpatients during participant recruitment and data collection at the hospital or the nursing home involved in the study. The investigator is also a member of a committee that is a joint initiative between the hospital and the palliative care team. As a member of the committee, the investigator participated in quarterly meetings and contributed to committee initiatives, including hospital staff education about palliative care and assisting in the development of criteria to better identify patients with unmet

Table 3.1. Strategies to Achieve Qualitative Rigor

Credibility: Results Are Believable.	*Dependability: Study Design and Results Can Be Replicated.*	*Transferability: Results Can Be Transferred to Other Settings.*
Study diary: self-reflection	Field notes: short description of context/activity during interviews	Field notes: description of context during data collection
Review/debrief: confront bias and assess assumptions	Study diary: detailed description of intuitive thoughts during data collection and analysis	Study diary, field notes, audit trail: clear details so others can replicate the design
Field notes: descriptions during data collection	Audit trail: analytic memos during coding	Sample: descriptive statistics to describe the sample
Longitudinal design: prolonged engagement with two interviews and five chart reviews	Triangulation: interviews and chart review data	Audit trail: review steps with sponsor and methodologist

Adapted from Bloomberg & Volpe (2008) and Guba (1981).

palliative care needs. Evidence-based criteria and committee input were used to develop criteria to identify patients with unmet needs.

Protection of Human Subjects

Eligible patient/resident human subject categories included the following classifications, three of which are described in Figure 3.1:

- Participants who are patients/residents and have medical decision-making capacity, can consent for self, and can participate in an interview
- Participants who are patients/residents and do not have medical decision-making capacity but who can assent to research activities and participate in an interview
- Participants who are patients/residents and do not have medical decision-making capacity, cannot assent to research activities, and cannot participate in an

interview

- Participants who are an LAR or an LAR-identified family member of a participant who consents to participate in interviews for patient/resident participants who cannot participate in an interview

Vulnerable Population

Although this study did not involve the following vulnerable populations—fetuses, neonates, pregnant women, or prisoners—it did involve individuals with life-limiting illness or complex serious illness who were hospitalized patients, nursing home residents, or an eligible participant's LAR. Older individuals with life-limiting illness in a hospital and nursing home or an LAR are potentially vulnerable and may have consented to participate in this study due to a real or perceived benefit, hope for improvement in the condition, or the desire to help others. Protections for vulnerable participants included the following:

- A clearly written consent form(s) and additional time allowed to explain the study
- A consent form in large font (14 point) and written at an eighth-grade reading and literacy level
- An option to have the consent form read out loud
- An option to involve an LAR in the consent process
- Verbal reconsent and reassent throughout the study
- Decision-making capacity determined by information in the medical record and confirmed by a palliative care team member in the hospital
- If a participant became fatigued during an interview, he or she was given the

opportunity to take a break or end the interview.

The investigator was especially aware of the symptoms a resident participant might experience and thus assessed for discomfort, fatigue, and exhaustion. If these symptoms occurred, the interview ended, and the resident was encouraged to notify the nursing home staff for assistance. If the participant was unable to call, the investigator asked the participant for permission to notify the nursing home staff. Attention to the emotions and fatigue levels of LARs/family members participating in interviews was also noted, and breaks were offered as needed.

Protections for Participants

As part of the study, the investigator had access to personally identifiable information (this was granted through a request for waiver of HIPAA authorization for research at the hospital and through the signed informed consent after enrollment). The consent forms identified participants by name and were stored in a locked, secure location at the investigator's office after a copy of the form was provided to the participant or LAR. An enrollment log was stored in a locked, secure location at the investigator's office. Participants were assigned numbers, and the chart review data, records, and interviews were identifiable only by participant number. The enrollment log was the only method for identifying the participant name with the assigned participant number and was stored separately from the consent forms in a locked file in the investigator's office. A professional transcriptionist transcribed the interviews verbatim using only the participant ID number. The audio-recorded interviews were secured on an encrypted computer and destroyed when analysis was complete. The data were collected,

managed, and protected by the investigator on an encrypted and password-protected computer.

Potential Risks and Additional Identified Protections

This research posed minimal risk to participants. Participants (residents and/or LARs/family members) may become upset when discussing life-limiting illness; therefore, careful attention was given to assessment of participant reactions to questions and probes during interviews. When a participant was found to not have the ability to answer interview questions because of a change in mental or medical status, the interview was stopped, and the participant was approached again the next day. If a participant did not want or was unable to continue with the study, he or she was offered disenrollment from the study. Protection for older adults experiencing serious life-limiting illness included limiting interviews to 20 min and allowing for frequent breaks during an interview. This helped diminish fatigue and potential burden on participants. These actions also protected LARs/family members who were participating in the interviews.

The investigator used verbal verification to confirm continued willingness to participate in the interviews. The participant was reminded that the interview was being recorded. Confidentiality was maintained by providing privacy during interviews. Interviews were conducted in a private area at the nursing home or a location of the participant's choosing (e.g., an office or resident room), with the investigator and participant present, as well as any person the participant requested.

Benefits of Participation

The minimal risks to which participants were exposed in this study were reasonable in relation to the potential benefits provided by this study. Although the benefits may not have directly affected the participants, they included gaining more knowledge about the characteristics of effective palliative care delivery during and following transition from the hospital to a nursing home.

Importance of Knowledge Gained

There is no systematic study in the literature about follow-through and outcomes after patients experience an inpatient palliative care consult, leave the hospital, and are admitted to nursing homes without hospice support. Knowledge from this research study will be used to optimize care delivery for other ill and frail nursing home residents. The risks outlined above are minimal compared to the benefit of knowledge this study has generated for future patients.

Chapter Summary

This chapter detailed the study methodology. Qualitative descriptive research is a valuable approach to research problems when little is known about a topic, as the method allows for depth and breadth during data collection and analysis. In addition, qualitative description keeps researchers close to the data, allowing them to describe participants' experiences.

Through the use of semistructured interviews and chart reviews, data were collected from participants in a community hospital palliative care program and nursing

home. First and Second Cycle coding were used for data analysis to develop categories and themes that represented the rich description of participant experiences. The investigator's awareness of credibility, dependability, and transferability during qualitative data collection and analysis maintained rigor. Special attention to ethical issues protected human subjects. In conclusion, the results of this study expand understanding and knowledge about the delivery of palliative care after hospitalization in a nursing home.

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CHAPTER 4

POSTACUTE CARE IN NURSING FACILITIES AFTER HOSPITAL-BASED PALLIATIVE CARE CONSULT

Abstract

The objective of this analysis was to describe the continuity of older adults' palliative plan of care from the hospital to the nursing facility. A longitudinal qualitative descriptive study with interviews and medical record reviews was conducted in a community hospital and nursing facility in the mid-Atlantic United States. Participants included older adults with a life expectancy of at least 7 days, who received an inpatient palliative care consult and discharge to a nursing facility without hospice. Semistructured interviews and medical record reviews were used to elicit information about patient/family preferences, clinical course, and care processes at hospital discharge and up to four times after nursing facility admission. Data were analyzed using inductive content analysis techniques. Twelve older adults with a mean age of 80.9 years were enrolled. Nine participants were female, and three were African American. Analysis of interview transcripts and abstracted medical records revealed three themes: goal discontinuity, prognosis incongruence, and worsening symptoms. Study findings suggest that continuity of care preferences and communication between health care settings is

inconsistent following palliative care consult. Ongoing communication between settings to readdress prognosis, goals of care, and symptoms—the central tenets of palliative care—is lacking. Efforts to improve access to comprehensive palliative care delivery after hospitalization and during nursing facility transitions are greatly needed.

Introduction

Palliative care is an important interdisciplinary approach to health care for older adults living with advanced or serious life-limiting illness and complex care needs.[1,2] Despite being promoted as an effective method for delivering high-quality care to residents with life-limiting illness, palliative care is not widely available in the nursing home setting.[3-6] Barriers to palliative care include inadequate care-setting transitions, poor communication among clinicians, nursing home staff concentration on assigned duties over a focus on resident-centered care, and payment structures.[4,7-11] Consequences include unintended emphasis on aggressive rehabilitation over palliative goal-oriented care,[6] little acknowledgment of residents' values and preferences for palliative care,[12] and missed opportunities for symptom management such as psychosocial and spiritual support.[13]

The need for effective palliative care throughout care transitions has been widely endorsed. The Agency for Healthcare Research and Quality[14] recommends increased research about palliative care across settings, including continuity of palliative care between the hospital and nursing facility. Effective care transitions are seen as an important way to reduce expensive, avoidable hospital readmissions.[15,16] Both researchers and clinicians emphasize that care transitions are especially important for those patients

not receiving hospice upon hospital discharge[17,18] and for frail elders with complex care needs who use the posthospital Medicare skilled nursing facility (SNF) benefit.[19,20] There has been increased concern about use of the SNF benefit in the last few months of life, including the inability of most SNF patients to access the Medicare hospice benefit.[19]

A limited number of studies have examined the care and outcomes of older patients after hospital discharge during a nursing home stay when palliative care is provided, especially for those not referred for hospice care.[21] The purpose of this chapter is to describe the continuity of older adults' palliative plan of care from the hospital to the nursing facility by answering the question, What recommendations made during a hospital palliative care consult are followed through and received by residents in the nursing facility?

Methods

Setting

Between January and December 2014, potential participants who were planning discharge to a participating nursing facility were recruited from a palliative care team. The hospital and nursing facility (each with 250–300 beds) were located in the mid-Atlantic United States. The facility was chosen because it was identified as the most frequent nursing facility discharge location for patients after being seen by the hospital's palliative care team. During the study period, concurrent care models combining curative and hospice care were not available, and no formal system was in place for palliative care consultation and/or follow-up in the nursing facility. Nursing facility residents were also not known to visit the affiliated hospital's outpatient palliative care clinic.

Institutional Review Board approval was obtained from the University of Utah. Research review committees at the hospital and nursing facility approved the protocol. Staff at both the hospital and nursing facility were provided with an in-service about the study purpose.

Sample

Purposive criterion sampling identified patients who received an inpatient palliative care consultation with a discharge plan to the participating nursing facility. Eligibility included adults who (a) were English speakers, (b) were 60 years and older, (c) had a life expectancy of at least 7 days, and (d) had decision-making capacity and the ability to complete a 20-min interview. If an eligible participant was not decisional or could not participate in an interview, the legally authorized representative (LAR) was contacted (Figure 4.1). Patients enrolled in hospice at hospital discharge were excluded because of evidence that better palliative care outcomes are achieved with hospice care.[19] When data were found to be abundant and powerful in answering the research question within and across participant cases, participant study enrollment ceased.

Participants were recruited as soon as possible after receiving a palliative care consultation and a discharge plan that included the participating nursing facility. To identify potential participants, the palliative care team census was reviewed daily for eligible participants. A palliative care team member or the researcher approached the individual or the LAR in person or via telephone. Written informed consent was obtained from either the patient or the LAR up to 48 hr after hospital discharge.

Information was not collected on the specific reasons eligible participants

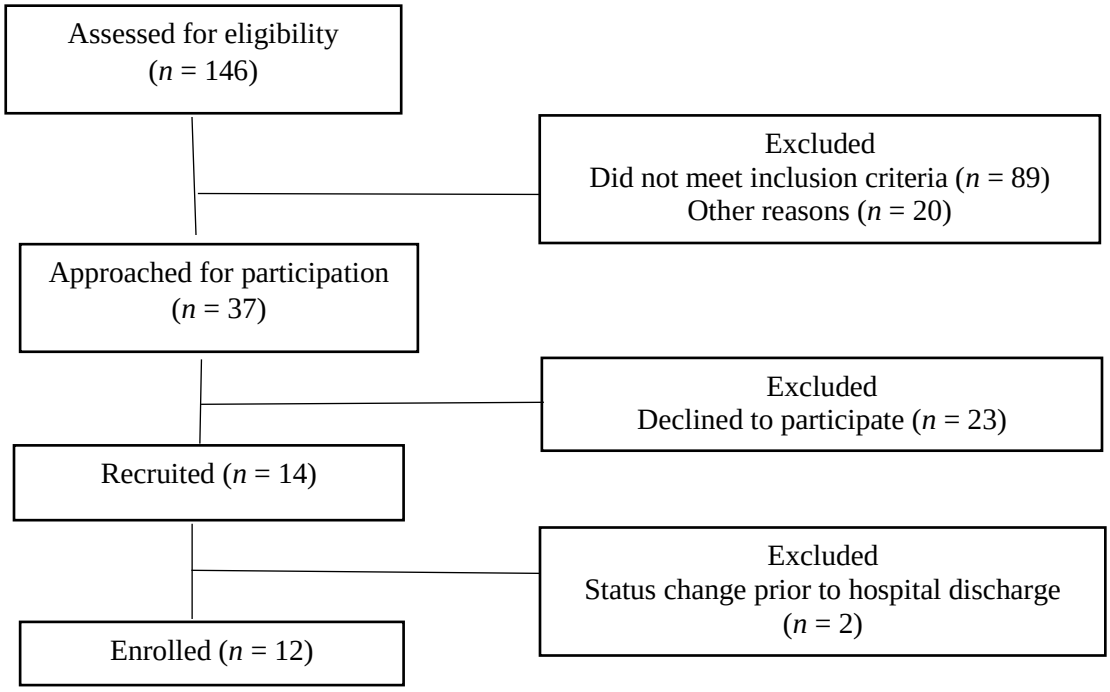

Figure 4.1. Enrollment Schema

declined participation after learning about the study. Often, the fast pace of hospital discharge led to situations in which patients and families faced multiple decisions and unanswered questions about care, which may have influenced decisions about study participation. Initially, this posed a threat to recruitment, but alterations in study procedures ameliorated recruitment issues.

Data Collection and Procedures

Medical Record Audit

Medical record audit tools were developed and revised based on expert opinion to collect information five times, from hospital discharge through 100 days after nursing facility admission (from the hospital record at discharge and from the nursing facility

record at 24–48 hr, 7 days, 21 days, and 100 days). Text about clinical course and care processes was copied, de-identified, and stored on an encrypted computer. The medical record was reviewed to (a) determine pain and symptom assessment, management (e.g., pharmaceutical and nonpharmaceutical interventions), and outcomes (e.g., relief or improvement); (b) psychosocial and spiritual support; (c) advance-care planning conversations, which included goals-of-care discussions, family meetings, and care-planning discussions and outcomes (e.g., decisions about care based on personal values and preferences); (d) nursing, medical, and rehabilitation care; and (e) nursing facility discharge disposition and health care utilization, including rehospitalization. Special attention was paid to presence of the palliative care consultation and hospital discharge summary, as well as care goals as documented on nursing facility admission note (e.g., objectives, goals, plan of care).

Interviews

Data collected during two interviews with each participant or the LAR at 7 days and at 21–30 days after nursing facility admission were used to determine which recommendations made during the hospital palliative care consultation were followed through and received by participants in the nursing facility. Interview guides were developed and revised after pilot testing. Interviews lasted 10 to 50 min and were digitally recorded and professionally transcribed. Field notes were written during and after the interviews and medical record reviews.

Data Analysis

Textual data from medical record audits and interviews were uploaded and organized chronologically by participant case and managed using NVivo v9 qualitative data analysis software. The first author completed medical record audits a median of four times (range 2 to 5) for each participant; incomplete data were attributable to death or discharge. The 15 interviews resulted in 264 pages of single-spaced transcripts (Table 4.1). Accuracy of transcribed interviews was verified through comparison to audio recordings.

Care trajectory matrices, from hospital discharge to 100 days after nursing facility admission, were constructed using the medical record audit. Data were coded using In Vivo and Descriptive coding methods guided by inductive content analysis techniques.[22,23] Reflective analytic notes were embedded in the trajectory matrices,

Table 4.1. Cases Included at Each Data Collection Point

Event	Hospital Discharge	Nursing Facility Admission	7 Days After Nursing Facility Admission	21–30 Days After Nursing Facility Admission	100 Days After Nursing Facility Admission
Medical record review completed (total = 50)	12	12	11 (discharged to another facility *n* = 1)	8 (discharged to another facility *n* = 1; death *n* = 3)	7 (discharged to another facility *n* = 1; death *n* = 4)
Interview completed (total = 15)	—	—	8 (discharged to another facility *n* = 1; death *n* = 1; LAR* unavailable *n* = 2)	7 (discharged to another facility *n* = 1, LAR unavailable *n* = 1, death *n* = 3)	—

*LAR, legally authorized representative.

and coded interview text was linked to trajectories to expand and add details to the care trajectory. The analysis was then guided by Pattern coding methods; the authors compared similarities and differences among coded data and each case longitudinally and identified overarching categories.[23] The categories were examined and defined by characteristics of the coded data. Then the categories were compared using matrices; relationships within and between the categories were identified for core variable(s) and properties reflecting follow-through of palliative care consultation. Categories were then grouped by properties to develop themes. Two authors (JGC and PH) met weekly during analysis to discuss codes, categories, and initial themes. The National Quality Forum's (NQF's) *Preferred Practices for Palliative and Hospice Care Quality* provided a framework for comparison of the themes during final analysis (Table 4.2).[17] An audit trail, as well as methodological, analytic, and theoretical memos, was entered into a study diary from the project outset.[24] These notes also reflected how codes, categories, and themes were developed.

Results

Twelve older adult patients (mean 80.9 years, range 62–95) were enrolled (Table 4.3). Participants were seriously ill at the time of study enrollment—six died within six weeks of nursing facility admission. Five received tube feeding or hemodialysis. Diagnoses included advanced cancer, end-stage renal disease, progressive neurological disorders, end-stage cardiac disease, and cerebrovascular accident with dysphagia. Six were rehospitalized at least once, and two were transferred to the emergency department twice. One participant desired a higher level of rehabilitative care and was discharged to

Table 4.2. Summary of Themes (Related to National Quality Forum's (NQF's) *Preferred Practices for Palliative and Hospice Care Quality*)[17]

Theme	NQF Preferred Practice
Goal Discontinuity	1. Formulate, utilize, and regularly review a plan of care based on values, preferences, goals, and needs of the patient and family and broadly disseminate the plan to all professionals involved in the patient's care.
	2. Timely and thorough communication of the patient's goals, preferences, values, and clinical information upon transfer between healthcare settings
	3. Present hospice as an option to all patients and families when death within a year would not be surprising.
	9. Conduct regular patient and family care conferences with members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.
Prognosis Incongruence	1. Formulate, utilize, and regularly review a plan of care based on values, preferences, goals, and needs of the patient and family and broadly disseminate the plan to all professionals involved in the patient's care.
	2. Timely and thorough communication of the patient's goals, preferences, values, and clinical information upon transfer between healthcare settings
	4. Educate patients about disease, prognosis, and potential interventions to help them to make informed decisions about their care.
	9. Conduct regular patient and family care conferences with members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.
Fluctuating Symptoms	5. Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.
	6. Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
	7. Measure and document psychological symptoms (anxiety, depression, delirium, behavioral disturbances) using available standardized scales.
	8. Manage psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.

Table 4.3. Patient Characteristics

Age, years (range 62–95)	80.9
Gender	
Male (*n* = 3)	25%
Female (*n* = 9)	75%
Race	
African American (*n* = 3)	25%
White (*n* = 9)	75%
Decisional status	
Makes own decisions (*n* = 5)	41.7%
LAR* makes decisions (*n* = 7)	58.3%
Spouse (*n* = 2)	28.6%
Adult child (*n* = 3)	42.8%
Extended family member (*n* = 2)	28.6%

*LAR, legally authorized representative.

another facility three days after admission. Although none of the participants accessed hospice care while in the nursing facility, two were transferred to a hospice inpatient unit after rehospitalization. Of the seven patient participants who were not decisional, four were completely nonverbal and unable to participate in the interview. Analysis of interview transcripts and abstracted medical records revealed three themes: goal discontinuity, prognosis incongruence, and worsening symptoms (Table 4.4).

Goal Discontinuity: "Continuity Is Huge"

Discontinuity was related to inadequate communication, including insufficient transfer of records to the nursing facility, a lack of information exchange about care preferences, and a mismatch between staff and family expectation, as well as to interference of health care system policy. All patients or their family members engaged in conversations about goals of care facilitated by the hospital's palliative care team. As documented in the hospital record, goals ranged from comfort care to aggressive

Table 4.4. Summary of Themes, Definitions, Categories, and Exemplar Quotes*

Theme	Definition	Categories	Exemplar Quotation(s)
Goal Discontinuity: "Continuity Is Huge"	Discontinuity related to inadequate communication (i.e., exchange and understanding of print and verbal information), including insufficient transfer of records to the nursing facility; lack of information and/or a mismatch about care preferences among patients, families, and staff; or interference of health care system policy.	Hospital palliative care team plan (MR) Nursing facility plan (MR) Hospital to nursing facility care (I) The goal (I)	"Because when I—I filled out the MOLST form. And I know when I signed for it, I did sign for my father to be treated. DNR does not mean Do Not Treat … but, in fact, the nurse sat down and said, 'Well you marked palliative care.'" The daughter indicated that the facility staff equated palliative care and DNR with CMO. —Mismatch between staff and family expectation
Prognosis Incongruence: "Prognosis Poor. Rehabilitation Potential Good"	A discrepancy in prognosis between the palliative care consultation or the hospital medical record and the nursing facility. Inconsistency was associated with an assumption that medical prognosis would improve with gains in functional status.	Hospital and nursing facility prognosis (MR) Rehabilitation (I)	"He needs a lot more therapy than he gets, but he's only entitled to certain amounts." —Family member talking about spouse
Worsening Symptoms: "It Seems Episodic."	Symptoms experienced in the hospital are the same as or are more prominent after nursing facility admission.	Palliative care consultation "for symptoms" (MR) Symptom presence in nursing facility (MR) Worsening symptoms (I)	"They give him his crushed meds yesterday, and within minutes, he—was vomiting." —Family member describing recurring emesis

*MR, medical record data; I, interview data; MOLST, Medical Orders for Life Sustaining Treatment; DNR, do not resuscitate; CMO, comfort measures only.

life-prolonging interventions; however, one patient had care preferences documented in the hospital discharge summary, palliative care consult, and nursing facility admission notes upon transfer.

The hospital discharge summaries of 11 participants were present upon nursing facility admission; nine of these summaries stated that palliative care had been consulted during the hospitalization but did not elaborate on the content or outcomes of the palliative care consultation. Moreover, the written palliative care consultation care notes were found in only three of the 12 medical records that accompanied the patient to the nursing facility. The summaries included statements such as "palliative care was consulted," "hospice and palliative care were offered," "Consultation: Palliative Care," and "palliative care has discussed goals of care." Specific details of the palliative care consultation, care-planning discussions, recommendations, and plans for future care were not included. Of all 12 nursing facility admission medical notes, three indicated that the palliative care team had seen the participant; two of the three residents were receiving "end-of-life care," as noted in the nursing facility record. In five cases, the hospital's palliative care team had offered hospice, which was then declined by the patient and/or family. Only once was hospice reoffered by the nursing facility team during discharge planning to a resident's home.

In one instance, the hospital palliative care team recommended comfort care with hospice support for a participant who was a long-term resident of the facility. However, the LAR reported challenges with implementing a plan for hospice services because those services could not be accessed when the patient was receiving care under the Medicare SNF benefit.[25]

When asked about formal communication with the staff to discuss goals, the daughter of one 75-year-old long-term resident replied, “We haven’t met, except for one time. There’s been no meeting over here about care plan or nothin’.” The wife of an 87-year-old patient replied, “only when I ask” and “only if I bring it up,” when asked if the nursing home staff communicated with her about the plans for future care.

Prognosis Incongruence: “Prognosis Poor. Rehabilitation Potential Good”

The prognosis during palliative care consultation for 11 participants was documented as poor in the hospital medical record. Alternatively, a fair or good prognosis and rehabilitation potential were noted in the nursing facility admission notes for eight participants and not specified for three patients. For one patient, the prognosis and rehabilitation potential were noted as poor. Two of the three patients with no prognosis noted were admitted with medical orders for comfort-oriented care and were expected to die at the facility; the third was a nonverbal patient with advanced dementia and a newly placed feeding tube who received aggressive life-prolonging treatment. All 12 accessed the SNF benefit, which included physical, occupational, and/or speech therapy; care for wounds and new feeding tube placement; and intravenous antibiotics.

For eight patients whose rehabilitation prognosis was considered fair or good, the documented goal was to improve their health and functional status. For one patient whose prognosis was poor but who wanted life-extending treatments, the goal stated in the medical records was to “maintain status” with “skilled therapy.” Phrases such as “get better,” “get more independent,” and “to get out, to get out. To get well and get out” were

expressed in interviews with participants as the ultimate purpose of the nursing facility admission. Rehabilitation was the dominant focus of care, despite a poor medical prognosis.

Several participants perceived that improvement in strength or independence would offset illness progression and improve comfort. When asked about what her father with end-stage cardiac disease needed to feel comfortable in the facility, a daughter responded, “He wants his independence back. That’s what he’s striving for, is to regain his strength so that he can be more independent.” When asked how she wanted to spend her time in the coming days, a long-term care resident who was completely dependent for activities of daily living and had advanced cancer said, “Feeling, uh, that I—that I am feeling able to do for myself.” Others viewed skilled nursing and rehabilitation as a way to exert control over a serious and progressive illness. A daughter responded about her mother, “We’re trying to get more on the schedule that we were on before this whole thing started—so that she can lead a relatively normal life.”

Worsening Symptoms: “It Seems Episodic.”

Several participants’ consults for palliative care at the hospital indicated that symptom management was a priority. When severe pain was noted, for example, the palliative care team recommended inpatient hospice, which the patient declined. For two participants with dysphagia and aspiration, the palliative care team recommended intermittently holding tube feeding, lowering the rate of tube feeding, and attempting daily pleasure feeding with six small meals. These recommendations were implemented by the hospital attending team and followed through at the nursing facility.

Upon nursing facility admission, multiple symptoms were noted in the medical record. Symptoms occurred simultaneously and included pain, nausea, vomiting, dyspnea, insomnia, wounds, anxiety, depression, fever, constipation, cough, dysphagia, and itching. However, many participants reported difficulty expressing symptoms to the nursing facility staff because of their own reluctance, weakness, or disability. One LAR reported, "He won't ring the nurse's bell. In fact, he-he can't even get to it." Another said about her father's pain, "He wouldn't tell anybody else." In other cases, the nursing facility staff did not recognize symptoms. Family caregivers felt frustrated with both participants' powerlessness to notify staff and their belief that the staff was unable to better assess and treat pain. According to a family member, "He have [*sic*] actions where he'll let you know that he's in pain; . . . for some reason, they are, like, they don't see it." Another LAR reported the challenge between pain relief and the sedating effects of opioids, "Cuz she likes to know if she's in pain. She doesn't wanna be completely out of it." Often symptoms were associated with an inability to participate in rehabilitation—for example, being sleepy, fatigued, or short of breath delayed therapy participation.

Symptoms such as nausea and vomiting were common and often related to dysphagia and feeding tubes. Other participants' nausea and vomiting were directly related to eating, and oral intake was severely affected. When asked about eating, one participant said, "Only in the morning. I can't eat the rest of the day."

Discussion

The purpose of this study was to describe which recommendations made during a hospital palliative care consult are followed through and received by residents in the

nursing facility. The findings indicate an absence of documentation, resulting in inadequate communication of care preferences, incongruent prognoses between the hospital and nursing facility, and symptoms that required ongoing assessment and management. Even though all study participants received palliative goals-of-care conversations (e.g., advance-care planning) while hospitalized, the content and outcomes of those conversations were not routinely provided to the nursing facility.

First, findings of this study are consistent with the widely recognized problems associated with communication during transfers to nursing facility.[26] Missing, inaccurate, and conflicting information from hospital discharge records can lead to serious delays in resident care, including pain management and rehospitalization.[27] Poor communication about care preferences also leads to staff confusion, miscommunication with families, and possible errors.

In this study, the absence of substantive documentation regarding the palliative care consultation is concerning. Without proper information exchange about goals of care at nursing facility admission, the facility staff is left to speculate about care preferences, even when a Medical Orders for Life Sustaining Treatments form or an advance directive is available that states advance-care planning. Several participants relayed their frustration with poor communication and the disjointed care it caused. Findings revealed that facility staff did not frequently discuss advance-care planning. Mismatch between participants' and nursing facility staff's perceptions were likely exacerbated by the dearth of advance-care planning conversations after nursing facility admission.

Second, clear explanation of prognosis, assessment of the patient's and family's understanding of prognosis, and staff awareness of prognosis are needed. Prognosis

incongruence may lead to mixed messages and result in confusion and discontinuity regarding goals of care. Disease prognosis and functional or performance status prognosis are two different ways to organize information and recommend care for older adults with serious illness; each should inform the other about expected outcomes of the care trajectory. In this sample, however, improving functional status was viewed to mean stabilizing and improving overall health despite poor prognosis, evident illness progression, and end-of-life symptom burden.

Third, there is a need for regular, frequent symptom reassessment and management. During hospitalization, most participants did not have documented problems with symptoms, though many experienced symptoms after nursing facility admission. This finding is consistent with other research reporting symptom burden and unmet palliative care needs after nursing facility admission[28,29] and demonstrates the limited reach of inpatient palliative care teams. Community palliative care program development is needed to provide ongoing services to postacute care residents in nursing facilities.

Our findings suggest several areas for future work. Most pressing are policies that prevent many residents who use the SNF benefit to simultaneously use the Medicare hospice benefit. Only in rare cases, when the diagnosis for hospice care is not related to the diagnosis for SNF care, can a resident qualify for both benefits. Multiple participants qualified for and were offered hospice care during hospitalization; however, none enrolled during their stay in the nursing facility. In one case, the SNF benefit incentivized a family not to use hospice care because the SNF benefit paid for the nursing facility room and board, and the hospice benefit did not. The SNF benefit is intended for only

short-term use after a three-day hospital stay, for skilled nursing assessment, rehabilitative therapy, and complex interventions to help improve or maintain a condition and prevent it from getting worse.[25] The Medicare hospice benefit provides aggressive symptom management and psychosocial and spiritual support but does not allow payment for room and board.

How much a terminally ill patient's goals of care match the basic purpose of the SNF benefit to promote improvement is uncertain. Patients' and families' confusion may grow when deciding care preferences at end of life, while efforts are being made to improve functional status with the SNF benefit. Research on innovative payment and delivery models and policy reform is critically needed to better meet older adults' needs during SNF care at the end of life. Findings of this study further support the case for policy reform.

Additional research should employ longitudinal designs with large sample sizes to compare the outcomes of care in nursing facilities after palliative care consultation (e.g., symptom management, burdensome transitions, costs) for traditional Medicare SNF beneficiaries matched to Medicare hospice enrollees. Understanding the long-term outcomes of palliative care consultation for those who do not elect or qualify for hospice care is needed. Further, there is a need to highlight how well palliative care teams and nursing facilities are readdressing care preferences throughout the illness trajectory to ensure concordance between preferences and delivery of care. Patients and families with low health care literacy may not receive high-quality palliative care.[30] Therefore, additional research investigating the ability to understand complex treatment choices associated with palliative care is needed.

Limitations

Because the nursing staff was not interviewed or observed during this study, it is unknown how much verbal communication occurred at handoff from hospital to nursing facility and vice versa (e.g., informal conversations about values and goals between nursing staff and patients/residents or LARs). Relying on medical records leaves many questions related to absent documentation. For example, not everything done for the resident was actually recorded in the medical record. Finally, interviews may have resulted in respondent reactivity (e.g., participants respond in certain ways because they want to be socially accepted).

Conclusion

The NQF's *Preferred Practices for Palliative and Hospice Care Quality* highlights the importance of care continuity during setting transitions for seriously ill patients.[17] Table 4.4 crosswalks study findings to the recommendations. Specifically, this study highlighted three areas that can improve care continuity between settings. First, there needs to be thorough communication of goals, values, and care preferences. Second, patients in nursing facilities and their family members need ongoing disease and prognostic information to better make health care decisions, and hospice care should be offered and made available when needed. Third, symptoms should be managed effectively and in a manner acceptable to the patient and family. For older adults, there are many points of potential disruption of palliative care along the continuum of care. Special attention must be paid to providing high-quality palliative care.

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CHAPTER 5

PALLIATIVE CARE AFTER HOSPITALIZATION: TYPOLOGIES OF PATIENT OUTCOMES AND EXPERIENCES IN NURSING FACILITIES

Abstract

Palliative care consultation during hospitalization is an increasingly common event for older adults living with advanced illness and complex care needs. The objective of this qualitative descriptive study was to describe the care trajectories and experiences of older adults admitted to a nursing facility following a hospitalization during which they received a palliative care consultation. Twelve English-speaking older adults over 60 years old with a life expectancy of at least 7 days who received a hospital palliative care consultation and discharge to a nursing facility without hospice were enrolled. Care trajectories were mapped using clinical information from medical records of hospital discharge up to 100 days following nursing facility admission. Fifteen interviews were audio recorded, transcribed, imported into the QSR NVivo v9 software program, and combined with each participant's medical record data. Content analysis was employed on the combined dataset. The mean age was 80 years (range 62–95). All participants received palliative care consultation–facilitated goals-of-care conversations during hospitalization and were admitted to a nursing facility under the Medicare skilled nursing

facility benefit. Rehospitalization was common (n = 7), and half of the sample died by study day 40. The three main care typologies were *Rehabilitative/Restorative Care*, *Patient–Family Caregiver Incongruence in Care Goals*, and *Comfort Care Continuity*. Heavy emphasis on recovering functional status through rehabilitation and skilled nursing care, despite considerable symptom burden and poor prognosis, was identified. Despite debilitating symptoms, many frail older adults with very limited life expectancy and their family caregivers may perceive that rehabilitation will improve physical function. This perception may contribute to inappropriate, ineffective rehabilitative/restorative care.

Introduction

National attention to palliative care program development and research has focused primarily on hospital-based programs.[1-3] A majority of patients seen by hospital palliative care consultation teams who survive to discharge will undergo a transition to another care setting—very likely, a nursing facility.[4-6] For older adults, careful transition at discharge after a hospital palliative care consultation is of great importance.

German researchers reported "stable" care trajectories after hospital palliative care (i.e., staying in the place of discharge until death). However, the majority of these patients were discharged to inpatient hospices. The researchers also found that patients supported by outpatient palliative care moved less between care settings.[7] Benzar et al. studied the experience of U.S. patients and their families with discharge planning after palliative care consultation. This study, however, did not focus exclusively on nursing facility care.[8] This team learned that the topics most concerning to caregivers and patients after hospital discharge were symptom management, prognosis, and whom they should

talk to when questions arise. Further examination of nursing facility care from the patient and/or family perspective after hospital palliative care consultation can inform clinical practice and guide initiatives to promote palliative care in nursing facilities.[9]

The purpose of this chapter is to describe the care trajectories, including indicators of care and long-term outcomes (e.g., advance-care planning, symptom management, psychosocial support, spiritual care, nursing, rehabilitation, medical care), and care perceptions for patients discharged to a nursing facility after receiving an inpatient palliative care consultation.

Methods

Setting and Sample

Two settings in the mid-Atlantic United States were involved in the study: a hospital with a palliative care consultation team and a nursing facility several miles from the hospital where the majority of the patients requiring nursing facility placement were referred. The nursing facility provides long-term, short-stay, and dementia care. It also contracts with a local Medicare-certified, not-for-profit hospice agency. Most data were collected in the nursing facility after hospital discharge.

Patients were eligible to participate if they were 60 years or older with a life expectancy of at least 7 days, were English speakers, and received a palliative care consultation while hospitalized. The palliative care team determined a patient's decision-making capacity. If the potential participant lacked decision-making capacity or could not participate in a 20-min interview (e.g., nonverbal, dysarthria), a legally authorized representative (LAR) (e.g., designated surrogate or health care power of attorney) was

contacted for participation. A palliative care team member or the researcher initially contacted the potential participant or LAR to inform them about the study. The researcher then met with interested potential participants or LARs, presented verbal and written details about the study, and obtained signed informed consent. Assent was obtained prior to interviews. The University of Utah Institutional Review Board approved this study; the participating hospital and nursing facility research review committees both reviewed and approved the study.

Procedures

Semistructured interviews were conducted with participants, their LARs, or both one week and one month after nursing facility admission. Interviews were guided by an interview guide (Table 5.1) reflecting current practices in palliative care. Additional topics included perceptions of care delivery, including medical, nursing, and rehabilitative care. The interview guide was pilot tested and revised before use. The first author conducted face-to-face interviews in a quiet, private location; the interviews were audio recorded with the participant's permission. Interviews ranged from 10 to 50 min and were professionally transcribed verbatim. Transcribed interviews were then compared to the audio recording to verify accuracy and note additional emotions that may not have been captured in the transcript (e.g., vocal strain and pitch associated with sadness, crying, or laughing).

An audit tool was used to collect data from medical records at the hospital and nursing facility at five time points: at hospital discharge; at nursing facility admission; and then at 7 days, 30 days, and 100 days after nursing facility admission. The data

Table 5.1. Semistructured Interview Guide

Describe the type of care that you need to feel comfortable. Can you give an example of a time when you received this kind of care here? Is this the same care as in the hospital? Can you talk more about this type of care? Tell me about how the staff has talked to you about this type of care.
Tell me about what is most important to you. How do you want to spend your time in the coming days? How is this the same or different from now? Can you talk about how you decided that?
Tell me about [insert symptoms noted in hospital palliative care consult and chart review]. So how is it going with those symptoms? Are they better or worse than in the hospital [or last interview]? How does the staff talk to you about [insert symptoms]? What does the staff do for your [insert symptoms]?
How do you want the staff to support your feelings [insert feelings of depression, anxiety, sadness referenced in the palliative care consult or chart] you have while you are here? Can you give an example of a time when you felt supported in that way here? Is there a time these things got in the way of having a good day?
Tell me about meetings or talks you have had with the staff here. What did you tell them? What did they ask you?
Is there anything else I have not asked that you think I should know?

collection time points were chosen based on the following: within 7 days, a plan of care is in place, and the resident is "settled" in; between 21 and 30 days, a care planning meeting has typically occurred; and at 100 days, the long-term plan for care can be determined. The hospital medical record was used to obtain demographics, medical diagnoses, medications, advance-care planning, and details of the hospital palliative plan of care. The nursing facility's medical records were reviewed to determine pain and symptom management assessment, interventions, and outcomes; psychosocial and spiritual support; advance-care planning conversations, including goals of care, family meetings, and care planning discussions and outcomes; and nursing, medical, and

rehabilitation care delivered to participants (including hospitalization and emergency department visits).

Analysis

All data were entered and managed in NVivo v9 care trajectory matrices that chronologically constructed care over the 100-day study period; they were also entered into individual case files that included interview data. The matrices were detailed, graphical representations of days 1–100 and corresponding events (e.g., symptoms and medical care, such as primary care provider visits, emergency department visits, hospitalization, discharge, and death). These matrices were used to develop a collective representation of the care experience. Using In Vivo and Descriptive First Cycle coding methods, described by Saldana, the interview transcripts and medical record data were analyzed separately.[10] During Second Cycle coding, we employed Pattern coding to combine coded data and to guide the development of categories and themes.

Care trajectory matrices were also examined using Pattern coding, and typologies were identified.[11] Data summary tables were used to organize each identified typology and participants' coded data and outcomes. Coded interview responses were also entered into a data summary table to examine participant and/or LAR perceptions of symptom management, adherence to goals of care, and psychosocial support. This organization of data allowed for further examination of data subsets according to typology.

Trustworthiness

Strategies to reduce bias; enhance credibility, reliability, and transferability; and achieve trustworthiness were used. Interviews and medical record reviews provided methodological triangulation.[12] A study diary comprised of memos, field notes, and investigator reflections was maintained. An audit trail detailing analytic decisions was used to document coding decisions.[13] Meetings with experts in qualitative data analysis, gerontology, and palliative care provided input on codes, categories, and themes. To establish interrater reliability and consistency, the first author developed a coding scheme (a codebook identifying codes, definitions, and examples).[14] The second author independently coded six pages of data using the coding scheme. The two coders reached 95% consensus after discussing coding differences.

Results

Thirty-seven potential eligible participants were approached to participate in the study; of those, 23 declined. Although 14 signed informed consent, two were ineligible due to an unexpected change in hospital discharge location. In the end, 12 participants were enrolled (Table 5.2).

Participants were (a) decisional and interviewed alone (n = 3), (b) decisional and interviewed with a family member per request (n = 1), (c) not decisional but able to participate in interviews with their LAR (n = 3), and (d) nonverbal (n = 2) with their LAR participating in the interview. Medical record audits were completed a median of four times (range 2–5) for each patient participant from hospital discharge through 100 days after nursing facility admission. Data collected from 50 medical record reviews and

Table 5.2. Sample Characteristics

Age, years (range 62–95)	80.9
Gender	
Male (*n* = 3)	25%
Female (*n* = 9)	75%
Race	
African American (*n* = 3)	25%
White (*n* = 9)	75%
Decision Status	
Makes own decisions (*n* = 5)	41.7%
LAR makes decisions (*n* = 7)	58.3%
Spouse (*n* = 2)	28.6%
Adult child (*n* = 3)	42.8%
Extended family member (*n* = 2)	28.6%

15 interviews were analyzed. Attrition was related only to patient death (Table 5.3). No participants withdrew from the study. All participants received palliative care team–facilitated goals-of-care conversations (defined as advance-care planning) in the hospital, had a poor prognosis during hospitalization, and used the Medicare skilled nursing facility (SNF) benefit upon nursing home admission. None accessed hospice care in the nursing home. Three unique typologies were identified from the care trajectories: *Rehabilitative/Restorative Care, Patient/Family Caregiver Incongruence in Care Goals*, and *Comfort Care Continuity*. Each typology, described below, had unique features.

Rehabilitative/Restorative Care

For the seven participants in this typology, diagnoses included end-stage renal disease, end-stage cardiac disease, metastatic cancer, and complications from cerebrovascular disease. Health care use (e.g., medical care) was high; most participants were rehospitalized once, and one was rehospitalized twice. Participants were visited at

Table 5.3. Cases Included at Each Data Collection Point

Event	Hospital Discharge	Nursing Facility Admission	7 Days After Nursing Facility Admission	21–30 Days After Nursing Facility Admission	100 Days After Nursing Facility Admission
Medical record review completed (total = 50)	12	12	11 (discharged to another facility *n* = 1)	8 (death *n* = 3)	7 (death *n* = 1)
Interview completed (total = 15)	—	—	8 (discharged to another facility *n* = 1, death *n* = 1, LAR* unavailable *n* = 2)	7 (LAR unavailable *n* = 2)	—

*LAR, legally authorized representative.

least once by a nursing facility primary care provider to address symptoms or manage a change in status; one patient was seen eight times. All had medical orders for SNF benefit physical and occupational therapy for the first 30 days after nursing facility admission, and several had medical orders for speech therapy. Several received intravenous antibiotics or complicated wound care, even though improvement was unlikely.

The majority of participants in this typology were able to be interviewed, but their goals often seemed unrealistic due not only to dependence on nursing staff for activities of daily living but also to disease stage and progression. When discussing independence as a source of comfort, an LAR responded, “I think that’s why he closes his eyes when he answers, um, questions. And I think it’s also—avoidance.” The patient recognized at that point that he was not going to be independent again.

During the hospital palliative care consultation, participants and LARs said that although they might consider hospice in the future, there was a strong desire to achieve improvement or stabilization. Participants said, “It's a bit too soon to be thinkin’ about that,” “I’m gonna just wait and see what happens, and then—you know,” and “Hospice came by once. During hospitalization. I said, ‘Please. Do not use that word in front of my mother,’” indicating hesitancy to pursue hospice care.

Medical care resulting in transitions were common. At times, goals were revisited at the emergency department, and an immediate transfer to inpatient hospice was initiated for uncontrolled symptoms. More than half (n = 4) of participants in this typology died at the hospital, inpatient hospice, or nursing facility within six weeks of admission.

In the nursing facility, moderate to severe persistent symptoms indicated deteriorating medical status and resulted in hospitalization. When discussing symptoms, one LAR reported, “They get worse here. That’s why he sent down to the hospital. Um, most of the time, this is where it starts—and then, he gets sent to the hospital. They patch him up a quick fix and send him back here.”

Psychological support interventions for anxiety, depression, and agitated behaviors were only in the form of medications. Some participants and LARs did not feel supported by staff. When the LAR of a nonverbal participant was asked about how staff handle agitation, she reported, “I don’t think they help him with that. Um, I really don’t think they help him with it.” There was no documented spiritual support beyond chaplain visits during hospitalization.

Patient/Family Caregiver Incongruence in Care Goals

For these participants, the palliative care consultation recommendations and the previously expressed patient goals were not congruent with the LAR decision maker's goals. Inconsistencies occurred at the person level, as patients and family members were unwilling or unable to accept the poor prognosis and make decisions consistent with previously expressed preferences for care. Within this typology, the three participants were not decisional and did not contribute to their goals or care preference discussions in the hospital. All three had a gastrostomy feeding tube. Diagnoses included progressive neurological disease (including stroke and dementia with complete activities of daily living dependence) and advanced cancer. Health care use was high; each participant had between six and nine visits by a primary care provider in the nursing facility, and all were transferred to the emergency department or were hospitalized at least once. All received physical, occupational, and speech therapy during the study period; care was provided for new feeding tubes and wounds. None died during the study period. Outcomes included discharge to a private home and long-term care in the nursing facility.

There was reluctance on the part of LARs to accept deteriorating medical status. In referring to the palliative care consultation, an LAR said, "They told me, you know, that at some point in time we could call hospice in. . . . But right now I think that may be a little premature." With an LAR present, a participant acknowledged that the goal was to go home "before I die. I just see my life gone." For this participant, however, the medical orders reflected aggressive care, including CPR and mechanical ventilation.

Symptoms were also persistent and burdensome. Pain, constipation, dyspnea, complications associated with dysphagia and tube feedings, and discomfort with wound

care were prevalent. One participant felt that not being able to drink "a cold water" unless a therapist was present greatly impacted quality of life. Tube feeding aspiration was not seen as problematic; as one LAR stated, "It was just the aspiration and pneumonia that sent her to the hospital. . . . We can control the aspiration." Anxiety and depression were common and treated with medications. No psychosocial or spiritual support was noted at the nursing facility. Participants and LARs did feel supported by the staff: "They're understanding." "You know, they're very concerned and caring, I have to say that."

Comfort Care Continuity

The features of this typology focused on comfort, and all involved family members and health care providers agreed on the plan of care. For those two patients admitted to the nursing facility under "comfort measures only," symptoms were minimal. Pain, constipation, and fever were managed with medications. Goals were discussed in terms of "being as comfortable as possible." "Do not hospitalize" orders were written in the nursing facility medical orders. Neither had transfers out of the facility prior to their death. Hospice care was recommended but not used due to system-level factors including reimbursement and payment policies. Participants died within four weeks of nursing facility admission (one died prior to any interview time points).

These participants received between one and three primary care provider visits in the nursing facility (on admission and for symptom management). Nursing care focused on pleasure feedings, bowel care, and pain management. Treatment for depression was in the form of medications only. No spiritual support was noted in the medical record or reported in interviews.

Despite the focus on comfort, these participants received occupational and speech therapy evaluations and care under the Medicare SNF benefit. When discussing speech therapy, an LAR reported, "They actually tried speech therapy, but to help her swallow is more or less—it really—it wasn't doing anything so. And that's when they decided to adjust the diet."

At the nursing facility system level, SNF benefit care was inconsistent with preferences. Traditionally, this benefit provides posthospital SNF care at a skilled level for a condition that will stabilize or improve (i.e., the occupational and speech pathology evaluations and treatments). There were clear indications and recommendations for hospice care that were not acted on after palliative care consultation. Nursing facility staff were able to treat symptoms evidenced by a low symptom burden. No life-prolonging interventions or burdensome transitions were used at the end of life. Table 5.4 summarizes the themes.

Discussion

The three typologies offer a new and rich description of older adults' experiences of care after hospital palliative care consultation and nursing facility admission. Each typology was informed by varying and complex individual care trajectories. Commonalities among all participants included facilitated goals-of-care discussions while hospitalized, overwhelmingly poor prognoses, and use of the Medicare SNF benefit upon nursing facility admission. Differences across the typologies were evident and characterized by alignment among the prognosis, palliative care consultation, care preferences of the participant and decision maker, and the health care system's influence

Table 5.4. Summary of Themes/Typologies, Definitions, and Exemplar Quotes

Theme/Typology	Definition	Exemplar Quotation(s)
Rehabilitative or Restorative Care (*n* = 7)	Plan and goals at nursing facility transfer focused on aggressive rehabilitation and interventions to improve the participant's overall condition, despite a poor medical prognosis during hospitalization.	"But when she asked me, 'What are you going to do?' I knew, without hesitation, that I was going to fight. And that's basically the last thing I remember saying or thinking was, fight." "His heart rate keeps dropping too low, and the antibiotics itself [*sic*] is not actually helping him."
Patient/Family Caregiver Incongruence in Care Goals (*n* = 3)	Underwent life extending treatments in the nursing facility, despite advance-care planning documentation and/or information obtained during interviews that revealed participants did not want that care.	When talking about a newly inserted feeding tube (decision was made by family member), a participant expressed, "Get that thing—get it out. I think it's awful. … I've suffered every day."
Comfort Care Continuity (*n* = 2)	Advance-care planning documentation reflected desire for natural death and palliative or supportive care only. Consistency between the palliative care consultation and family and nursing staff at the facility and primary care providers was noted.	"It's—you know, and we go around with different scenarios and come—as a family—come to the best decision that we feel that she would want. You know, for herself. It's not necessarily about us. It's about what she wants and—and her needs."

on care. These findings shed light on several serious care-delivery problems.

These data suggest that after palliative care consultation, our health care system delivers fragmented, ineffective, and inefficient care. In all cases, study participants needed 24-hr care at hospital discharge. For those caregivers who have no options to provide care at home, nursing facilities offer care they cannot do themselves. Patients and family caregivers then accept what comes with nursing facility care, even though it might not be realistic or aligned with goals.

First, the SNF benefit supports patients' goals that focus on aggressive rehabilitation and interventions to improve an overall condition, despite a poor medical prognosis. Hope for functional improvement is supported by interventions that are delivered along with the SNF benefit. Words and phrases used by participants and LARs when discussing goals, including "stronger," "better," and "more independent," support this notion. The prospect of improvement is strengthened by the SNF benefit, regardless of expected medical decline. Concern arises in these situations because functional improvement is often not realistic due to continued progression of an underlying serious illness. In these situations and at times of uncertainty, time-limited trials would encourage revisiting goals frequently with plans to pursue less aggressive care when indicated.[18]

Second, patients and their families should be supported to make treatment decisions in alignment with stated preferences and, thus, honor the resident's self-determination and autonomy. Past research demonstrates that when caring for ill residents, nursing facility staff often feel swayed by family caregivers' care preferences and practice ineffective communication strategies.[19]

Third, health care resources are being used inefficiently and ineffectively. In this

study, rehospitalization, emergency department visits, and medical care use were high. Palliative care during hospitalization for those with complex illness is associated with decreased costs.[20,21] Community palliative care that provides ongoing connection and participation in care is important, may reduce rehospitalization and emergency department visits, and may limit unwanted care. Care that focuses on aggressive symptom management, frequent goals-of-care discussions, and psychosocial and spiritual support should be recognized as skilled palliative care and reimbursed as such under the SNF benefit, without the need for rehabilitative and restorative interventions.

Lastly, additional measures should be taken to make sure palliative care consultation recommendations made during hospitalization follow patients to their postdischarge setting. Inpatient teams can take extra care to provide patient education materials and written instructions after consultation.

Limitations

The study of more cases may have produced different results, including the use of hospice care. Interviews that may have resulted in respondent reactivity (e.g., participants modify responses because they misunderstand terms or they want to be socially accepted). It is also possible that not everything that was done for the resident was actually recorded in the medical record, resulting in missing data. For example, were there informal conversations about values and goals between nursing facility staff and participants or LARs that were not documented?

Conclusion

Frail older adults with very limited life expectancy and their family caregivers may perceive that rehabilitation will improve physical function even when it will likely not. This perception may contribute to inappropriate, ineffective rehabilitative and restorative care after an inpatient hospital palliative care consultation and nursing facility admission. Throughout the care trajectory, open honest communication about limited life expectancy and goals, values, and preferences for care should be readdressed frequently to formulate a plan of care congruent to a patient's values and wishes.

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CHAPTER 6

CONCLUSION

Introduction

This chapter provides a summary of the study purpose, methods, and results. Next, there is an interpretation of the major findings and a statement of important conclusions. The conclusions from the study address the aims and research questions. Limitations and challenges, clinical and policy implications, and recommendations for future research conclude this chapter.

Summary

The purpose of this study was to describe the continuity of palliative care, experiences and perceptions of care, and outcomes in the nursing facility for residents after receiving a palliative care consult during hospitalization. A qualitative descriptive approach utilizing medical record reviews and semistructured interviews was used to answer the following specific aims and research questions (RQs):

Aim 1) Describe the continuity of a patient's palliative care plan from the hospital to the nursing home.

RQ 1: What palliative care recommendations made during hospital palliative care consult are followed through and received by residents in the nursing home?

Aim 2) Describe the experience of patients admitted to the nursing home following discharge from a hospital with a palliative care consult**.**

RQ2: What are the immediate and long-term outcomes (e.g., goals of care, advance-care planning, symptom management, psychosocial support, spiritual care, nursing, rehabilitation, medical care) for residents in the nursing home after a palliative care consult during hospitalization?

RQ3: How do patients and/or families perceive pain and symptom management, adherence to goals of care, and psychosocial support in nursing homes after hospital discharge with a palliative care consult?

Because this is a new area of research, the research model (Figure 6.1) guided conceptual thinking and the methodological approach.

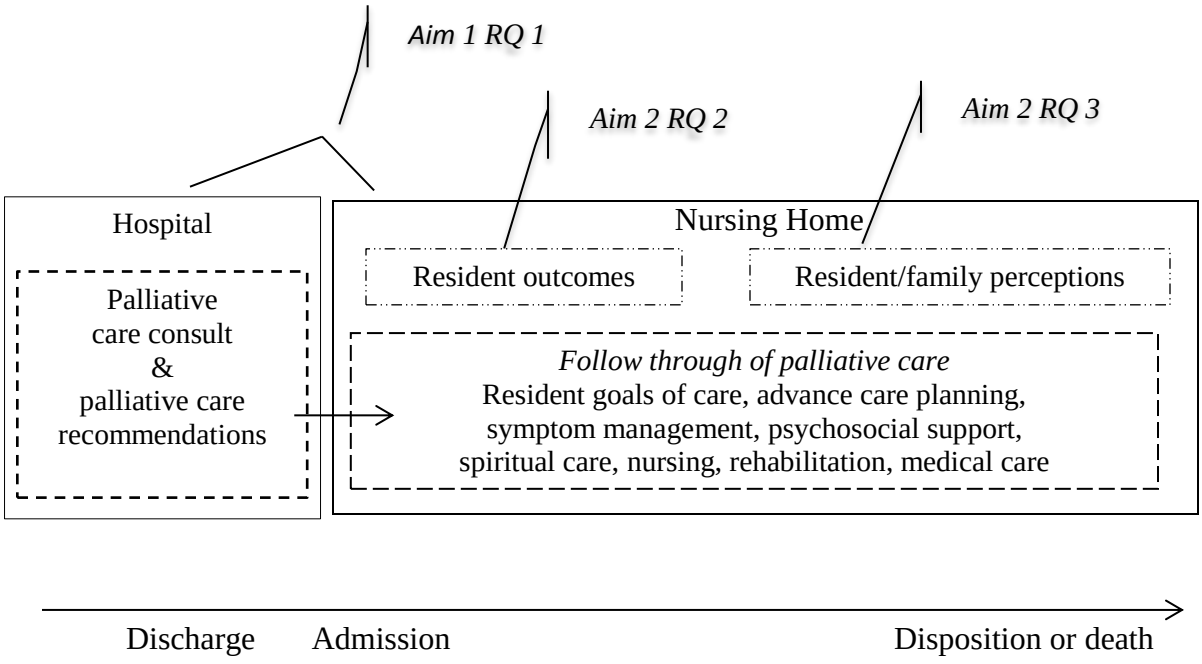

Figure 6.1. Research Model

A sample of 12 older adults in the mid-Atlantic United States who were 60 years or older, had a life expectancy of at least seven days, had received a palliative care consult during hospitalization, and were discharged to a nursing facility without hospice support were enrolled in the study. Participants' medical records at the hospital and nursing facility were reviewed for clinical information at five time points, from hospital discharge to 100 days after nursing facility admission. Individual medical record data were extracted, and care trajectories were mapped in a word-processing program. A professional transcriptionist transcribed audio recordings of the interviews. Medical record data, trajectories, and transcripts were imported into the NVivo v9 software program, in which data were organized and managed. Content analysis was employed to identify codes, categories, and themes through the use of First and Second Cycle coding (Saldana, 2009). Data were explored using techniques outlined by Miles, Huberman, and Saldana (2014).

Findings

The first major finding of this research is that the continuity from palliative care consultation during hospitalization to nursing facility admission and care was strikingly inadequate. Communication of care preferences was interrupted due to missed documentation, discrepancy between staff and families' perceptions of care goals, and system interference. Prognosis perceived by the health care providers was often incongruent between care settings, and symptoms were highly variable. Although symptoms may not have been problematic during hospitalization, burdensome physical symptoms appeared to increase after nursing facility admission (and after the palliative

care consultation). Psychological symptoms were also apparent but were often unaddressed at the nursing home. Together, these results indicate that there are multiple important unmet palliative care needs for patients admitted to a nursing facility after hospital palliative care consultation.

The second major finding of this research is that experiences vary for patients who receive care in nursing facilities after palliative care during hospitalization. During analysis, it became clear that the best method for describing the experiences among participants was through typologies. Perceptions of care were a part of each experience and were included within the typology in Chapter 5. The three main care trajectory typologies are *Rehabilitative/Restorative Care, Patient-Family Caregiver Incongruence in Care Goals,* and *Comfort Care Continuity*. Each of these is described below.

Rehabilitative/Restorative Care included patients with a poor prognosis who valued aggressive life-prolonging treatments that were not necessarily recommended by the palliative care team due to potentially poor outcomes. These patients experienced high symptom burden and high health care utilization. In this group, even though patients' wishes were respected (e.g., they received the care they wanted), their goals were not achieved because of poor overall survival.

Patient-Family Caregiver Incongruence in Care Goals was made up patients who were not able to make decisions and family caregivers who acted as decision makers. In these cases, aggressive life-prolonging treatments not aligned with the patient's previously stated goals were pursued. There was significant symptom burden and the highest health care utilization of all typologies (e.g., hospitalization, feeding tubes, primary care provider visits).

Comfort Care Continuity included those patients or LARs who accepted the palliative care team's prognosis and recommendations during consultation. In these cases, when prognosis was poor, comfort care that provided for a patient's natural death was followed through in the nursing facility. However, care preferences were not followed through when hospice care could not be used at the nursing facility (an example of system interference).

Overall, heavy emphasis was placed on providing services to older adults with the goal of recovering functional status through rehabilitation and skilled nursing care, despite considerable symptom burden and poor prognosis. All participants accessed the skilled nursing facility (SNF) benefit. Regardless of debilitating symptoms, many frail older adults with very limited life expectancy and their family members may have believed that rehabilitation would improve physical function. This belief may have contributed to inappropriate, ineffective care.

Conclusions

When compared to the nationally accepted guidelines for quality palliative care, these findings demonstrate major gaps (National Quality Forum, 2006). Comprehensive interdisciplinary assessment of goals, values and preferences did not occur at the nursing facility. Hospice was not offered to those who met criteria for admission. There was a lack of detailed communication about goals, values, and preferences after the palliative care consultation. Prognosis was not discussed and not revisited after facility admission. Patients and family caregivers were unable to make informed decisions about their care based on the benefit and burdens of treatment in light of the poor prognoses. All accessed

and receive the SNF benefit that may have prevented them receiving individualized end of life care due to the focus on recovering physical function.

These findings indicate that there are three main areas of breakdown along the continuum of care after hospital palliative care consultation. First, care-setting transitions pose significant barriers in the communication of care goals. Second, individual patient-level factors, such as reluctance to accept a poor prognosis and a family caregiver's decisions to not follow through on a patient's previously stated preferences for care, affect continuity of care. Third, system-level policy barriers impede person-centered, goal-focused care at the end of life in nursing facilities. For many residents, care is singularly focused on tasks determined by the payment benefit. For example, SNF care requires meeting goals for improvement in physical function, without regard for underlying progressive medical illness and symptom needs. In essence, once admitted to the nursing facility under the Medicare SNF benefit, application of the benefit puts residents on a predetermined routine in which the focus is on improvement rather than comfort, without a built-in mechanism to stop or revisit the goals.

There are limitations in this research project. First, the study of more cases may have produced different results, including the use of hospice care. However, after review of data from the participating hospital palliative care team over the one-year study enrollment period, only seven of 161 patients discharged to local nursing facilities elected hospice care after admission (two were at the participating nursing facility). Only one hospice provides care in this geographic location, so it is unlikely that patients would have used another hospice's services.

A second limitation is the use of interviews that may have resulted in respondent

reactivity, which occurs when participants modify responses because they misunderstand the interview terms or questions, they want to be socially accepted, or they simply respond unnaturally because they are being interviewed. To anticipate and lessen reactivity, participants were interviewed privately in a location of their choosing. When possible, the investigator asked questions using a participant's terms to increase common understanding of concepts, such as: "What do you mean by [insert phrase]?" or "Can you tell me more about [insert word]?" To improve recall and responses, participants were reminded about the palliative care team consultations during hospitalization and were provided with a description of the team member who saw them.

A third limitation is the possibility that not everything that was done for the resident was actually recorded in the medical record, resulting in missing data. For example, were there informal, undocumented conversations about values and goals between nursing facility staff and participants or LARs? Did clergy visit when the staff was not aware or did not note in the record? To anticipate and address this possible limitation, interview guides were designed to capture responses on these topics from the interviewees; as such, it is likely that these topics would have been reported.

Lastly, staff was not involved in this research. Eliciting nursing home staff perceptions of care after palliative care consultation may have provided additional data to confirm findings or uncover data missed in medical record review.

Challenges encountered throughout the year of enrollment and data collection included recruitment and timing of consent. Recruitment posed the biggest challenge. Although the palliative care team championed the study, workload and possible gatekeeping prevented team members from referring patients to the researcher. For

example, a palliative care team member may have voiced, “You would not want this person in the study.” To address these issues, several amendments to the study protocol were put in place, including a waiver of HIPAA authorization for recruitment, which permitted the researcher to screen medical records. In addition, the researcher developed and distributed to potential participants a one-page handout describing the study.

Timing of consent and data collection procedures also posed a challenge. Amendments were submitted to permit interviews to occur outside of a data collection window, with the LAR after a participant’s death, or at the participant’s personal residence after nursing facility discharge. Due to the fast pace of hospital discharge, an amendment was sought and approved to allow consent to occur 48 hr after hospital discharge (prior to any data collection) and in the location of the LAR’s choosing so that enough time was allotted to make a decision about participation.

Implications and Recommendations

The following clinical and policy implications and recommendations for future research conclude this chapter. Many patients seen for palliative care consultation die while still hospitalized. Those who survive may receive palliative care services through hospice care. Few palliative care resources exist for those who do not qualify for or who do not desire hospice care but who need additional services in nursing facilities. What can hospital palliative care teams do for patients who survive to discharge and do not use hospice? How can teams extend services beyond the hospital walls? There is a great need for community palliative care services. Hospitals should dedicate resources for palliative care teams to grow their services for patients after discharge, which is especially timely

as hospitals experience cuts in reimbursement for 30-day readmissions and some states move to population-based health care (e.g., all-payer hospital system modernization).

All-payer models transform the payment for hospital services from fee-for-service to overall population-based expenditures. The goal is to improve health care quality and care experience, while reducing costs through improved care coordination and prevention (Rajkumar et al., 2014). Collaboration between all health care agencies (e.g., hospital, community, long-term care) is essential for success. Moving palliative care into the community is a creative and innovative way for hospitals to improve transitions, reduce costs through preventing readmissions, provide high-quality health care, and improve the patient care experience for seriously ill older adults.

Palliative care teams have been shown to reduce readmission rates and costs when compared to usual care (Enguidanos, Vesper, & Lorenz, 2012; Gade et al., 2008). Although models exist to deliver palliative care in nursing facilities, reimbursement prohibits teams from growing. Traditional Medicare is currently structured to promote use of the SNF benefit for postacute care, because the facility receives a higher level of reimbursement. The benefit's payment structure favors rehabilitative or restorative care over comfort-focused care. Palliative care consultation models, though successful, meet challenges in that reimbursement under Medicare part B is restricted to billable services performed by clinicians. In addition, consultation relies on the facility staff to implement the recommendations, and many facility staff lack training in palliative care. Facilities cannot afford to invest in resources to train staff and expand internal palliative care services due to financial restrictions. Many facilities operate on restrictive yearly budgets and can only implement programs that demonstrate immediate financial revenue (Center

to Advance Palliative Care, 2008; Kelley & Morrison, 2015).

Access to palliative care is restrained by the regulatory system and institutional environment of U.S. nursing facilities. Herein rests not only an obstacle in palliative care delivery but also an inequality for residents of nursing facilities compared to those in other settings with palliative care resources. Innovative models funded by hospital systems are in great need. A pilot study of the cost savings and/or cost avoidance of palliative care for those in nursing facilities would be useful to make the financial case for expanding resources. Future research should include larger scale studies to determine the relationship between palliative care consultation timing and intensity of services on outcomes and care perceptions.

In conclusion, the findings of this research provide a foundation for research related to the continuity of palliative care from hospitals to nursing facilities. Three areas of potential breakdown in continuity include during care-setting transition, person-level characteristics, and system-level characteristics. Through system-level change, we may see improvement in transitions and care that is more consistent with prognosis and individual preferences.

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APPENDIX A

INTERVIEW GUIDES

Resident Participant Semistructured Interview Guide

We talked before about this research study when we met last time. Do you have questions? Is it OK if we talk now? I am interested in learning about care in the nursing home after being hospitalized and seeing the palliative care team in the hospital. I want to ask you a few questions about how you are doing now. As we discussed when I last saw you (or when I met you), I am going to record our conversation because I can't write everything down, and I don't want to miss anything. What you say to me is confidential (I will keep it private), though.

1. Describe the type of care that you need to feel comfortable. Can you give an example of a time when you received this kind of care here?

   Follow-up probes:

   a. Is this the same as in the hospital?

   b. Can you talk more about this type of care?

   c. Tell me about how the staff has talked to you about this type of care.

2. Tell me about what is most important to you.

   How do you want to spend your time in the coming days?

   Follow-up probes:

a. How is this the same as or different from now?

b. Can you talk about how you decided that?

3. Tell me about [insert symptoms noted in hospital palliative care consult and chart review].

   Follow-up probes:

   a. So how is it going with those symptoms?

   b. Are they better or worse than in the hospital [or last interview]?

   c. How does the staff talk to you about [insert symptoms]?

   d. What does the staff do for your [insert symptoms]?

4. How do you want the staff here to support your feelings [insert feelings of depression, anxiety, sadness referenced in the palliative care consult or chart] you have while you are here?

   Follow-up probes:

   a. Can you give an example of a time when you felt supported in that way here?

   b. Is there a time when these things got in the way of having a good day?

5. Tell me about meetings or talks you have had with the staff here.

   Follow-up probes:

   a. What did you tell them?

   b. What did they ask you?

6. Is there anything else I have not asked that you think I should know?

Legally Authorized Representative Semistructured Interview Guide

Remember when we last saw one another, we talked about this research study. I am interested in learning about your thoughts regarding the care [insert name] has received in the nursing home after being seen by the hospital palliative care team while in the hospital. I want to ask you a few questions about how things are going now. Do you have questions? Is this a good time for us to talk?

As we discussed when I last saw you (or when I met you), I am going to record our conversation because I can't write everything down, and I don't want to miss anything. What you say to me is confidential (I will keep it private), though.

1. Describe the type of care that [the resident] needs to feel comfortable. Can you give an example of a time when [the resident] received this kind of care here?

   Follow-up probes:

   a. Is this the same as in the hospital?

   b. Can you talk more about this type of care?

   c. Tell me about how the staff has talked to you about this type of care.

2. Tell me about what is most important to [the resident].

   How do you think [the resident] wants to spend their time in the coming days?

   Follow-up probes:

   a. How is this the same as or different from now?

   b. Can you talk about how you decided that?

3. Tell me about [insert symptoms noted in hospital palliative care consult and chart review].

   Follow-up probes:

a. So how is it going with those symptoms?

b. Are they better or worse than in the hospital [or last interview]?

c. How does the staff talk to you about [insert symptoms]?

d. What does the staff do for [insert symptoms]?

4. How do you want the staff here to support [the resident's] feelings [insert feelings of depression, anxiety, sadness referenced in the palliative care consult or chart] while [the resident] is here?

   Follow-up probes:

   a. Can you give an example of a time when you thought [the resident] was supported in that way here?

   b. Is there a time these things got in the way of [insert resident] having a good day?

5. Tell me about meetings or talks you have had with the staff here about [insert resident].

   Follow-up probes:

   a. What did you tell them?

   b. What did they ask you?

6. Is there anything else I have not asked that you think I should know?

7. I'd like to ask you a few things about yourself. What is your age? How do you describe your relationship with [insert resident]? How long have you been involved in the care of [insert resident]?

APPENDIX B

CHART/MEDICAL RECORD REVIEW DATA COLLECTION TOOLS

Hospital Chart Review Data Collection Tool (after consent signed)

Participant number _____ Today's date _____

Date palliative care consult completed _____

Medical decision-making capacity _____ yes ____no

Name/date of source document (copy and import PDF in NVivo) _____

Medical decision-making capacity confirmed by palliative care team member:

Role of member and date _____

If no, legally authorized representative name and contact information:

_____

Date of birth _____ Ethnicity _____ Race _____

Medical diagnoses (list)

_____

_____

_____

Palliative care diagnosis (if specified) _____

Payment source: Medicare Medicaid Private None Other _____

Medication list (copy and import PDF in NVivo) _____ (name of file)

Details of the hospital palliative plan of care:

1. Recommendations from palliative care team (copy consult and import PDF in NVivo)

   _____ (name of file)

2. Symptom management <u>assessment, interventions, outcomes</u> (circle below and copy relevant notes, and import PDF in NVivo) pain, dyspnea, nausea/vomiting, constipation, diarrhea, depression, anxiety, pruritis, skin care, dysphagia, anorexia, other _____

3. Outcomes of advance-care planning conversations

   Family meetings

   ___ yes (copy notes and import PDF in NVivo) ____ no

   Goals of care identified in chart notes

   ___ yes (copy notes and import PDF in NVivo) ____ no

   Medical Orders for Life Sustaining Treatments (MOLST) form completed

   ___ yes (copy and import PDF in NVivo) ____ no

   Advance Directives documented

   ___ yes (copy and import PDF in NVivo) ____ no

4. Psychosocial and spiritual support:

   Chaplain visits ____ yes (copy notes and import PDF in NVivo) ____ no

   Social worker visits ___ yes (copy notes and import PDF in NVivo) ___ no

5. Other notes:

<u>Nursing Home Admission Chart Review (24–48 hrs after admit) Data Collection Tool</u>

Participant number _____ Today's date _____

Date of birth _____ Ethnicity _____ Race _____

Medical diagnoses:

Payment source: Medicare Medicaid Private None Other _____

Medication list (copy and import PDF in NVivo) _____

Hospital discharge summary sheet on chart

___ yes (copy and import PDF in NVivo) ____ no

Medical diagnoses (list)

_____

_____

_____

_____

Palliative care diagnosis (if specified) _____

Medication list (copy and import PDF in NVivo) _____ (name of file)

1. Nursing home admission orders (copy and import PDF in NVivo)

   _____ (name of file)

2. Hospital palliative care consult on chart? _____ yes _____ no

3. Symptom management <u>assessment, interventions, outcomes</u> (circle below and copy relevant notes, and import PDF in NVivo): pain, dyspnea, nausea/vomiting, constipation, diarrhea, depression, anxiety, pruritis, skin care, dysphagia, anorexia, other _____

4. Outcomes of advance-care planning conversations

   Family meetings

   ___ yes (copy notes and import PDF in NVivo) _____ (name of file)

   ___ no

Care plan conference

___ yes (copy notes and import PDF in NVivo) _____ (name of file) ___ no

Goals of care identified in chart notes

___ yes (copy notes and import PDF NVivo) _____ (name of file)

___ no

Medical Orders for Life Sustaining Treatments (MOLST) form completed

___ yes (copy and import PDF in NVivo) _____ (name of file)

___ no

Advance Directives documented

___ yes (copy and import PDF in NVivo) _____ (name of file)

___ no

6. Psychosocial and spiritual support:

   Chaplain visits

   ___ yes (copy notes and import PDF in NVivo) _____ (name of file)

   ___ no

   Social worker visits

   ___ yes (copy notes and import PDF in NVivo) _____ (name of file)

   ___ no

7. Other notes:

Nursing Home Chart Review Data Collection Tool (to be used at 7 days, 21–30 days)

Participant number _____ Today's date _____

7 days _____ 21–30 days _____

Payment Source: Medicare Medicaid Private None Other _____

1. Symptom management assessment, interventions, outcomes (circle below and copy relevant notes, and import PDF in NVivo) pain, dyspnea, nausea/vomiting, constipation, diarrhea, depression, anxiety, pruritis, skin care, dysphagia, anorexia, other _____
2. Outcomes of advance-care planning conversations

   Family meetings

   ___ yes _____ dates (PDF imported in NVivo) _____ (name of file)

   ____ no

   Care plan conference

   ___ yes _____ dates (PDF imported in NVivo) _____ (name of file)

   ____ no

   Goals of care identified in chart notes

   ___ yes (copy notes and import PDF in NVivo) _____ (name of file)

   _____ no

   Medical Orders for Life Sustaining Treatments (MOLST) form completed

   ___ yes (copy and import PDF in NVivo) _____ (name of file)

   ____ no

   Advance Directives documented

   ___ yes (copy and import PDF in NVivo) _____ (name of file) ____ no
3. Psychosocial and spiritual support:

   Chaplain visits

   ___ yes (copy notes and import PDF in NVivo) _____ (name of file)

   ____ no

Social worker visits

___ yes (copy notes and import PDF in NVivo) _____ (name of file)

___ no

Type of care received (circle) Comfort care Medicare Skilled nursing facility benefit Long-term care Other _____

If under Medicare skilled nursing facility benefit

Physical therapy

___ yes (copy and import PDF in NVivo) _____ (name of file) _____ no

Occupational therapy

____ yes (copy and import PDF in NVivo) _____ (name of file) _____ no

Speech therapy

____ yes (copy and import PDF in NVivo) _____ (name of file) _____ no

Primary medical provider visit

___ yes_____ no, if yes, visit dates _____

Address symptoms (circle below and copy relevant notes, import PDF in NVivo)

_____ (name of file) pain, dyspnea, nausea/vomiting, constipation, diarrhea, depression, anxiety, pruritis, skin care, dysphagia, anorexia, other

_____

Discharge disposition and/or subsequent health care utilization: _____

Hospitalization?

__ yes (copy relevant notes and import PDF in NVivo) _____ (name of file)

Death? ___ yes (Date _____, Location of death_____)

Discharge to another location? ___ yes (Date _____, Location of discharge _____)

Admission to hospice care? ____ yes (Date ____, Location: facility, inpatient hospice, other _____)

Other notes:

Nursing Home Chart Review Data Collection Tool (100 days post admission)

Participant number _____ Today's date _____

Discharge disposition and/or subsequent health care utilization:

_____

_____

_____

Hospitalization?

___ yes (copy relevant notes and import PDF in NVivo) _____ (name of file)

Death?

___ yes (Date _____, Location of death _____)

Discharge to another location?

_____ yes (Date _____, Location of discharge _____)

Admission to hospice care?

_____ yes (Date _____, Location: (circle one) home hospice, facility hospice, inpatient hospice, other _____ (copy relevant notes and import PDF in NVivo) _____ (name of file)

Other notes: